ART THERAPY TECHNIQUES TO IMPROVE COPING STRATEGIES IN CHILDREN 7-18 YEARS OLD WITH A CHRONIC DISEASE.

by

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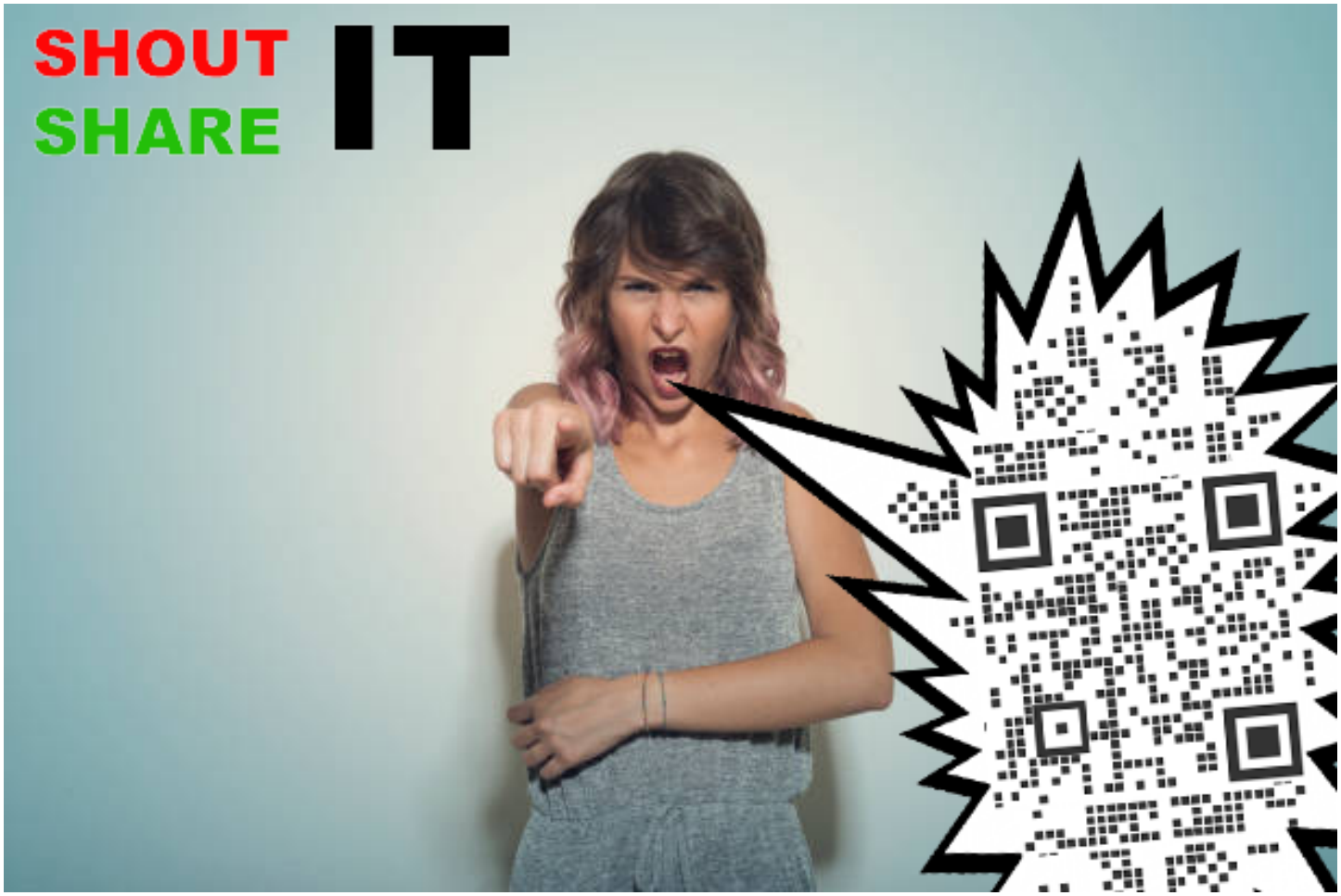
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Thesis submitted for the degree of Doctor of Philosophy in Public Health,
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"Dynamics of Health and Welfare"

Escola Nacional de Saúde Pública
From Universidade Nova de Lisboa
École des Hautes Études en Sciences Sociales

Supervisor
Prof. Maria Isabel Loureiro
Co-Supervisor
Prof. Philippe Roussin

To my mother

For every drawing we made together!

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ABSTRACT

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Few research studies have been conducted specifically focused on the change process in medical art therapy. A need for more intervention research in art therapy has been established. This research study focused on the results of an intervention study evaluating the use of art therapy with children coping with a chronic disease. Both baseline and after art intervention measures were employed to support the use of art intervention techniques with children diagnosed with a chronic disease to encourage verbal expressions of pain and modify coping strategies such as problem solving in response to the emotional burden of chronic disease and identify specific pivotal moments that bring about change process. Art intervention techniques were combined with Solution-Focused therapy approach (de Shazer, 1991) to create a treatment plan for children 7-18 years old diagnosed with a chronic disease.

Twelve children with chronic disease at the Hospital Santa Maria, Portugal, were randomized to an active art therapy or reference comparative group. Those in active group participated in seven sessions of art intervention for 60 minutes. Measures taken at the baseline, and after the final art intervention session including Formal Elements Art Therapy Scale applied to the Person Picking an Apple from the Tree scale, children version of Pain Coping Questionnaire, Adolescent Pediatric Pain Tool, and KidCope. The children assigned to the reference comparative group completed all evaluations at the same intervals as the children receiving art therapy but did not receive art therapy intervention.

The results of this study revealed that children who received art intervention services significantly increased their vocabulary describing pain as measured by APPT, and manifested more active coping strategies while dealing with the chronic disease, measured by PCQ and KidCope. The changing moments identified through the description of the seven intervention sessions, were measured from the post-session PPAT measuring Problem Solving coping strategy main scale factor.

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LIST OF ABBREVIATION

PPAT ……...Peron Picking an Apple from the Tree

HSP ……....Hospital Santa Maria

FEATS ……...Formal Elements of Art Therapy Score

PCQ ……...Pain Coping Questionnaire

APPT ……Adolescents Pediatric Pain Tool

ADHD ……....Attention Deficit Hyperactive Disorder

INTRODUCTION

INTRODUCTION

Amedeo Modigliani referred to his passion for painting as “The function of art is to struggle against obligation” (Sichel, 1967). Frank was 11 year old when I met him, waiting alone in the hospital room for his medication. At the age of 4 he was diagnosed with Epilepsy, and as the first born in the family, his parents had panicked. Frank, ceased to have a ‘normal’ childhood, occupied by hospital visits, medication treatment, and parental protection. Children with chronic disease carry the burden of a protracted health condition that obliges them to behave accordingly to what is expected from such situation. This project, unique in its content, tries to provide an entertaining task and discover the strengths as well as hidden talents needed to nourish children’s imagination and free time.

Children tend to exhibit coping mechanisms that equilibrate their emotional state. Unable to openly express the struggle, art intervention provides a new mission, allowing children to balance emotional and behavioral domains into a stable structure that promotes independence. This research combines art intervention with Solution Focused Approach therapy to empower children with chronic disease to recognize their health conditions and develop new coping mechanisms. The art is considered a struggle toward freedom to discover conscious and unconscious coping mechanisms alongside the real struggle with chronic health condition.

A chronic disease is a health condition that persists for more than three months in a year. Frequent hospitalizations and continued emergencies interfere with patients’ daily functioning and social interactions (Eiser, 1990). Around 10-20% of children suffer from a chronic disease, the most common of which is asthma (Hobbs, 1985). Chronic diseases cannot be cured, but treatments ameliorate some consequences of the disease and prevent overall deterioration.

Children with chronic disease are faced not just with challenges of achieving optimal growth and development in the cognitive, physical and psychosocial domains, but also with learning to manage their disease or handicap. For example, they must learn to comply with medical treatment and they must come to terms with parental concern and their self-image. Eliser (1990, p. 3) defined

the chronic disease as “...conditions that affect children for extended periods of time, often for life. These diseases can be “managed” to the extent that a degree of pain control or reduction of attacks (of asthma), ... can generally be achieved. However, they cannot be cured”.

In order to gain information about children’s psychosocial adjustments, most researchers have relied on questionnaires filled out by parents, teachers, or physicians by leaving aside the children’s experience (Eiser, 1990). In regards to the academic performance, children diagnosed with a chronic disease experience a high rate of absenteeism. Notably, these children develop phobia for school and truancy as they face difficulties interacting with their classmates. Sometimes they avoid approaching their peers, since they may misunderstand the diseases or may believe them to be contagious (Hamlet, Pelegrin, & Katz, 1988). Consequently, children with chronic disease may develop personality changes such as hyperirritability, narcissism, uncontrollable outburst of rage, and memory failure (Lavigne, & Faier-Routman, 1992).

Children have a limited vocabulary; therefore, when using verbal communication, parents, physicians, and even the counselors need to gear it towards the child’s level of understanding. In the best of cases, verbal exchange might take place along with an entertaining task, such as a board game. Creativity and art therapy are two compatible approaches to working efficiently with these children. Coping with a chronic disease makes them particularly vulnerable and in need of expressive outlets to revive imagination and spirit in spite of hospital routines and restricted environments.

Many things affect the way, in which children and young people experience pain. This is particularly true in the case of chronic pain. The child’s actual experience of pain is modified by the context in which the pain is evoked and does not necessarily relate to the actual intensity of pain (Carter, 1994); it includes cognitive, experiential, social, behavioral, emotional, physical, and contextual components (Gillies, 1995). All these factors play a part in the child’s eventual understanding of pain, and his/her ability to cope with it. Various models have been proposed that acknowledge the effect of internal and external factors on the child’s experience of pain (Varni et. al., 1996).

Family is a powerful means of socialization with respect to pain (Mathews, McGrath, & Pigeon, 1993). Positive family pain models and interactive family functioning (Kliewer & Lewis, 1995) may be effective in helping the child adjust and be less stressed. However, there is potential for the family to provide a negative model that reinforces pain symptoms (Gil, Williams, Thompson, & Kinney, 1991). If professionals assume negative modeling is taking place, then the families may find that the professionals tend to blame them for their child's pain. Without ignoring the possibility of negative influences, the family should be acknowledged as a rich source for helping to deal with the child's experience. Indeed, parental expertise can often be dismissed or ignored by professionals (McGrath & Finley, 1999), especially if the professionals' attitude is that the parents are part of the problem rather than the solution.

Finding the cause of chronic pain is complex, and children with undiagnosed pain are subjected to numerous investigations and referred to different specialists (Varni et. al., 1996). This results in their having to cope with many "new" medical encounters that may in themselves be stressful. The key of an effective medical encounter is good communication. Consequently, the heart of this project is to ease the communication that exists among the participants of the triangle: children, parents, and pediatricians. The center of the attention is dedicated to the children's experiences with the chronic disease and the coping strategies related to pain.

DEFINITION OF TERMS

Art Therapy

A human service profession in which art is used for creative self-expression, and for non-verbal, non-threatening expression of conflicts, concerns or interests. Behavior change and persona growth are encouraged through insights gained through experience. Incorporated the knowledge of art experience, psychology, human behavior, and visual symbols, with normal and abnormal cognitive graphic, and personality development. Art therapists

develop this extensive background through graduate level programs which require an intensive focus in three areas: studio art, psychology, and art therapy. Art therapist are part of treatment teams, as well as consultant administrators, and supervisors. Art therapy itself can be used diagnostically and therapeutically (Rubin, 1983).

Assessment

A projective technique used to provide information or insight into an individual's dynamics for treatment planning, as well as, "to generate information that can enable art therapists to use standardized assessment instruments predictively" (Wadeson, 1992, p.130)

Coping

A process by which a person deals with stress, solves problems, and make decisions. The process has two main components, cognitive and non-cognitive. The cognitive component includes the thought and learning necessary to identify the source of the stress. The non-cognitive components are automatic and focus on relieving the discomfort (Skinner & Zimmer-Gembeck, 2007).

Change Process Research

Change process research refers to the specification of models of change in specific in-session contexts. A focus on the process of the change to allow theoreticians and practitioners to explain how a particular set of interventions creates change in a particular therapeutic context (Greenberg & Johnson, 1988).

Chronic illness

An illness which is last-longing, it is not curable, an may impose limitations on an individual's functional capabilities (Eiser, 1993).

Formal Elements of Art Therapy Scale

A rating scale and manual which were developed by Linda Gantt, PhD, ATR (1993) to score pictures, obtained from the assessment, Draw a Person Picking an Apple from a Tree. The FEATS is comprised from 14 different scales, which ask the rater to score the drawing according to the formal elements of the drawing.

PART I

THEORETICAL FRAMEWORK

CHAPTER 1

CHILDREN COPING WITH A CHRONIC DISEASE

1. CHILDREN COPING WITH A CHRONIC DISEASE

1.1. The impact of chronic diseases on three domains of functioning: academic, psychological, and social features.

As far as academic functioning is concerned, it has been shown by several researchers that chronically ill children experience a higher than average rate of school absenteeism (Fower, Davenport & Garg, 1992; Fowler, Johnson, & Atkinson 1985). In two different studies (MacLean, Perrin, Gortmarker, & Pierre, 1992; Silva, Seras, & Jones et. al. 1987), children with chronic disease did not show lower performance in school, in comparison to "healthy" children. However, one study (Fowler, Johnson, & Atkinson 1985) found that twice as many children with chronic disease have a learning disability. On the later reviews of this study, critics conclude that the result should be interpreted with caution, as learning disabilities might come as a separate problem from the chronic disease, resulting in poor performance at school. On the basis of these studies it can be concluded that children with chronic disease do not show lower performance, despite higher absence rates.

Further referring to the literature, psychological functioning has been conceptualized in different ways. In most cases, psychiatric labels, such as depression, conduct disorder and anxiety disorder, were used to describe the problems of children with chronic disease. Most of the studies (MacLean, Perrin, Gortmarker, & Perin, 1992; Hamlet, Pelegrin, & Katz, 1988), reported that children with chronic disease had more behavior problems compared to children without chronic disease. A closer examination revealed that an increase in behavioral problems was mainly related to a higher level of internalizing problems, especially depression, somatic complaints, social withdrawal, and high anxiety. Lavigne and Faier-Routman (1992) reached the same conclusion, even though children's overall psychological adjustment was assessed on the basis of ratings provided by either mental health professionals or the children's parents.

Although, in Kashani et. al's study (1992), it is illustrated that no differences in

the occurrence of psychiatric diagnoses were found between asthmatics and non-asthmatics when the children themselves were the informants, but differences were found in parental reports. Lavigne and Faier-Routman (1992) offered an explanation for these inconsistent findings. They had noticed that effect sizes were generally higher in better controlled studies (i.e. when careful matching procedures had been done) and in studies where normative comparisons had been used.

Another psychological construct that has been studied extensively in relation to chronic diseases is the patient's self-concept. In two studies self-concept was measured in relation to a specific domain, behavior, intellect, and physical competence (Weston, Macfarlane, & Hopkins, 1989). Lavigne and Faier-Routman (1992) reported that the self-concept of children with physical disorders was significantly lower than that of healthy children, across all studies they sampled. However, these differences were no longer significant when careful matching was done, or when the children's scores were compared to the normal group.

Unfortunately, youth diagnosed with chronic disease may be at elevated risk to experience greater decline in self-concept because of the additional health burdens they experience during this developmental period. More broadly, stigma associated with certain chronic illnesses, particularly neurological disorders, can have detrimental effect on youth-reported social acceptance (Austin, Shafer, & Deering, 2002). The accumulation of these domain-specific effects has the potential to result in overall decline in self-concept among youth with chronic illness. As such, examination of global self-concept represents an important study construct that can be compared among individuals experiencing different health statuses. In contrast, some studies have reported no significant difference in global self-concept between the youth, with and without epilepsy (Ferro, Ferro, & Boyle, 2012) and juvenile arthritis (LeBovidge et. al., 2003). This may be attributable, in part, to heterogeneity in illness severity among the youth with chronic illness (Ohan & Johnston, 2002). The self-protective hypothesis predicts that youths with chronic illness that are threatened by a challenging task may hide feelings of inadequacy by exaggerating reports of self-competence, thus inflating self-concept (Diener & Milich, 1997). Youth

suffering chronic disease represent an important population for the study of self-concept because of their psychological vulnerability and hypothesized use of protective mechanisms to retain a sense competence.

Few universal effects have been reported regarding the social functioning of children with chronic disease and these children are at risk of being socially isolated, because peers sometimes have misconceptions about diseases (Lavigne and Faier-Routman, 1992). For example, peers may be inclined to think that the chronic disease is contagious or may be fascinated by the disease. Consequentially, they may avoid or overprotect the chronically ill child, which may hinder the development of a normal friendship with their peers (Spirito et.al. 1991). On the same study, Spirito et.al (1991) reviewed the literature on peer relations and social adjustment in children and adolescents with chronic disease. They concluded that as a group, chronically ill children do not experience poorer peer relations than healthy children. However, some children with certain chronic diseases have reported or exhibited difficulties in peer interactions.

1.2. Developing a definition of Coping

The conceptualization of coping describes a convergence between person-environment transactions occurring when the individual appraises a situation as being stressful. Lazarus and Folkman (1984) gave the most well-known and widely accepted definition of coping as a set of purposeful and volitional efforts that regulate personal and environmental aspects while dealing with stress. Furthermore, they labeled stressful situations as a perception of harm, threat, or challenge.

The majority of future researchers borrowed the concept of Lazarus and Folkman (1984) and extended/elaborated coping definition to develop empirical measurements of coping. Successively, they didn't explore the conditions of stressful situation, but rather cast stress into specific targets toward which coping is directed. On the first group of researches, targets referred mainly to stressful situations (problem-focused coping and negative emotions (emotion-

focused coping) (Aldwin & Revenson, 1987; Billing & Moos, 1981). Others focused only on one target instead, the emotional reactions, aiming to minimize the impact of the strain (Pearlin et.al., 1981).

Another group of researchers analyze “stressful” through specifying the dimensions of a situation that requires a coping response. Coyne et.al. (1981) describes the cognitive and behavioral efforts to manage environmental and internal demands affecting an individual as exceeding a person’s resources. Dewe (1987) divides coping into active and passive attempts responding to a threat situation and aiming to remove the threat or reduce the discomfort.

Folkman, Lazarus, Dunkel-Schettel, Delongis and Gruen (1986) define coping as a constantly changing cognitive and behavioral effort to manage the internal and external demands of transactions exceeding personal resources. This broad definition allows for various specific coping targets that are internal (e.g. emotional reactions) or external (e.g. the situation). Furthermore, the definition can subsume more specific dimensions of what individuals find “taxing” (e.g. uncertainty, important consequences).

The focus is on coping behaviors or processes rather than a stable coping ‘style’ or personality trait (Burke & Weir, 1980; Folkman, 1982; Goldstain, 1973). This focus is important for ultimate supplication of research findings to managerial interventions and training. If coping is conceptualized as a personality trait which is relatively stable across situations, coping research would have little practical value for managers except perhaps, in selection of placement decisions. If, on the other hand coping is amenable to behavioral or structural intervention and training, new tools for stress management can be identified.

This definition also distinguishes coping from coping effectiveness. That is, it defines coping in terms of what people do specifically without reference to whether or not it ‘works’. Definitions that cast coping in terms of its effects such as ‘preventing, avoiding, or controlling emotional distress’ (Pearlin & Schooler, 1978) contain implicit effectiveness criteria. That is, coping is ‘effective’ if it prevents, avoids or controls individual distress. Although avoidance or control of individual distress is one aspect of effectiveness measure, admitting a critical

one, organizations are interested in other effectiveness measures as well, such as performance or intention to quit. The wording of the conceptual definition of coping should not be confounded with effectiveness criteria. The integrative definition offered (Folkman et.al., 1986) does not allude to any specific criteria for coping 'effectiveness'. Coping, not coping 'effectiveness', is therefore appropriate to our interest in organizational stress because this focus does not construe bias for researchers regarding what constitutes effective coping.

Finally, this conceptual definition applies to stress that takes the form of challenge as well as harm or threat.

Table 1. Distinction among coping categories (Skinner et.al., 2003)

Distinction	Definition
Emotion-focused coping vs. problem-focused coping	"Coping that is aimed at managing or altering the problem causing the distress" vs. "coping that is directed at regulating responses to the problem" (Lazarus & Folkman, 1984, p.150)
Problem-focused coping vs. emotion-focused coping vs. appraisal-focused coping	"Dealing with the reality of the situation…. Seeks to modify or eliminate the source of the stress" vs. "handling emotions aroused by a situation… responses whose primary function is to manage the emotions aroused by stressors and thereby maintain affective equilibrium" vs. "primary focus on appraising and reappraising a situation...involves attempts to define the meaning if a situation" (Moos & Billings, 1982, p.218)
Responses that modify the situation vs. responses that function to control the meaning of the problem vs. responses that function for the management of stress	"Responses that change the situation of which the strainful experience arises" vs. "responses that control the meaning of the strainful experience after it occurs but before the emergence of stress" vs. "responses that function more for the control of the stress itself after it has emerged" (Pearlin & Schooler, 1978, p. 6)
Approach vs. Avoidance	"Cognitive and emotional activity that is oriented either towards or away from the threat (Roth & Cohen, 1986, p. 813)"
Engagement vs. disengagement	"Responses that are oriented toward either the source of stress, or toward one's emotions and thoughts" vs. "responses that are oriented away from the stressor or one's emotions and thoughts" (Compas et.al., 2001, p.92)
Control vs. escape	"Proactive take-charge approach" vs. "staying clear of the person or situation or trying not to get concerned about it" (Latack & Havlovic, 1992, p.493)
Primary vs. secondary vs. relinquishment of control coping	Efforts to influence objective events or conditions vs. efforts to maximize one's fit with the current situation vs. relinquishment of control (Rudolph et.al., 1995)
Volitional effortful, controlled vs. involuntary, automatic coping	Response to stress that involve volition and conscious effort by the individual vs. responses that are automatized and not under conscious control (Compas et. al., 1997)
Direct vs. indirect coping	Coping in which an individual emits an overt motors behaviors to deal with stressful events vs. coping in which "the organism responds to the stressful events by enlisting the aid of a conspecific" (Barret & Campos, 1991, p. 33)

Note: Higher Order Distinctions Among Coping Categories. Adopted from "Searching for the structure of coping: A Review and Critique of Category Systems for classifying ways of coping," by E.A. Skinner, K. Edge, J. Altman, & H. Sherwood, 2003, *Psychological Bulletin* 129 (2), p. 226. Copyright 2003 by the American Psychological Association. Adopted with permission.

1.3. 'Coping' definition and its components for children with a chronic disease

Children with chronic disease such as epilepsy, asthma, diabetes, cystic fibrosis, etc., are at great risk of social and psychological challenges. The child's chronic diseases are numerous and they can be classified into three groups based on their prognosis: (Deschamps, Maciaux & Salbreuz, et.al. 1981):

1- Illness and paroxysmal phenomenon (asthma, epilepsy, diabetes…)

2- Illness which weakens the child, affects the general condition of the child and sometimes reduces the expectations of life (cystic fibrosis, hemophilia, heart diseases, chronic renal insufficiency, arthritis…)

3- Malignant illness even fatale (cancer, tumors, AIDS….)

In recent years, coping with a chronic disease has been considered a major research area, fewer efforts have been made with respect to coping in childhood, presumably because of the variety of development issues to be considered (Feeney 2000). Interestingly, the developmental perspective currently has a new focus in adult coping research. Attempts have been made to integrate strategies of coping in various chronic conditions and medical context using a developmental perspective (Fuendeling 1998; Schmidt et.al. 2002 a, b) For instance, attachment theory has proven to be useful in explaining, from the perspective of emotion regulation, why some individuals are able to shift resourcefully from one strategy to another, whereas others restrain themselves to very rigid ways of coping (Schmidt et. al. 2002). As a result, a developmental perspective can shift the focus from an exclusively disease-orientated perspective to a more resource-orientated perspective. The second approach in this direction has evolved from studies indicating that the adults' health and illness behavior has some correlation and antecedents in such behaviors during childhood (Whiehead et.al. 1994). It is likely that early-adopted coping strategies will be activated again when the adult patients with chronic conditions experience symptoms. Furthermore, older children use resignation as a coping strategy more frequently than the younger children, reflecting a more mature understanding that nothing can be done about certain

problems that is characteristics of adolescents who have reached formal operations (Schowalter, 1993) or is related to a greater duration of illness in adolescents than children. De Ridder and Schreurs (2001) lean on a very important aspect of coping especially when related to health conditions in particular. These include the question of whether coping should be considered a trait or a state. Is coping style a function of global and stable individual characteristics, or is coping a dynamic, process oriented construct? This issue remains unexplained particularly related to an absence of psychosocial interventions explicitly devoted to the improvement of patient coping strategies. Given the extensive exploration of the stress coping psychologists involved in developing and providing interventions for the chronically ill have picked up framework in studies. Therapists appear as little concerned with coping as coping researchers with interventions (Lazarus, 1993; Somerfield, 1997).

1.4. 'Coping' factors' impact on chronic disease and pain

Pain coping strategies are the cognitive and behavioral responses displayed by patients to manage painful episodes. Coping efforts may be either adaptive or maladaptive, depending on their outcome in terms of pain relief, emotional adjustment, or functional status (Varni, 1995). Thus, coping is conceptualized as a process mechanism, not as an outcome measure (Varni, 1995). The assessment of both adaptive and maladaptive pain coping strategies may generate heuristic guidance in explaining the observed individual variability in pain perception, pain behavior, emotional adjustment, and functional status (Varni, 1995).

Although coping has been studied in pediatric pain population to some degree, these studies have focused mainly on coping with acute procedural pain (Branson, et.al., 1990; Siegel & Smith, 1989). In contrast, an extensive empirical literature has documented the significance of pain coping strategies on pain and adjustment in adult chronic pain patients (Jensen et.al. 1991). In particular, the development of the Pain Coping Questionnaire (PCQ) by Keefe and associates (Lawson et.al., 1990; Rosenstiel & Keefe, 1983) has stimulated

programmatic research, resulting in significant advances in the conceptual understanding of the prediction of pain and adjustment by adult-oriented pain coping strategies (Geisser, et.al., 1994; Jensen et.al., 1992). This research has evolved within the theoretical framework of an adult-oriented stress and coping conceptual model (Lazarus & Folkman, 1984).

Varni and Wallander (Varni & Wallander, 1992) have developed a pediatric stress and coping conceptual model to explain the demonstrated variability in children's adaptation to pediatric chronic physical disorders. This theoretical framework served as the heuristic paradigm for the conceptual development of the Bio-behavioral Model of Pediatric Pain, formulated by Varni (1995).

1.4.1. Psychological aspects of pain perception

Pain is an unpleasant sensory and emotional experience. People vary in gender, age, cognitive level, pain experience, familial, and cultural influences. These individual characteristics represent relatively stable influencing factors and shape how we generally interpret the various sensations evoked by tissue damage (McGrath, 1994). In contrast, the situational, behavioral, and emotional factors vary dynamically depending on the context, and further exert a profound impact on our pain perceptions. What people understand about the source of their pain, how they behave, and how they feel, are all factors that affects their pain. Thus, although the casual relation between an injury and a consequent pain sensation seems direct and obvious, even pain from an obvious injury is modified by a variety of factors (McGrath, 1994).

1.4.2. Pain in relation to age, cognitive level and gender

From birth, humans have the capacity to experience pain and express their distress through behavioral and psychological changes. At a very tender age, children can recognize and describe their feeling of "hurt". Children's understanding and descriptions of pain naturally depend on their age, cognitive level, and previous pain experience (Nilson et.al, 2010). They judge the strength and unpleasantness of any pain in comparison to sensations already experienced at some time in the past. The nature and diversity of previous pain

experience form a frame of reference for perceiving all new and future pain.

Unlike adults, children have a rapidly changing frame of reference as they mature and sustain more diverse types of pain sensitivity. Yet, despite their changing frames of reference, children at about 5 years of age begin to describe their pain not only according to its hurting aspects but also to its sensory attributes, such as the quality, intensity, duration, location, frequency, and unpleasantness that is experienced (Paiget & Inhelder, 1969). Children learn specific words to describe the various aspects of all their perceptions, words to denote different sounds, colors, and tastes. Similarly, they build a vocabulary of words to describe their pain so that they can communicate meaningful information about its unique attribute (McGrath, 1994).

Most studies of how children understand pain indicate that the children's ideas change with increasing age in a developmental pattern consistent with the Piaget theory (Piaget & Inhelder, 1969). Children mature into adulthood, all through understanding how to control pain by their own experience and describing pain in a language that represents those experiences. As adults, we describe both the physical and emotional aspects of pain with more sophisticated terminologies than children are capable of doing. We rely less frequently on concrete analogies drawn from personal experience and convey our understanding of pain and pain control in more abstract concepts. The study focuses on the changing frame of reference regarding pain and especially procedural pain on children diagnosed with a chronic condition.

1.4.3. Situational factors: expectations, control, and relevance

The term 'psychological factors' refer to an array of cognitive, behavioral and emotional characteristics that are intrinsic to an individual. These factors shape our interests is their role in affecting pain perception and pain behaviors, especially pain of unknown etiology (McGrath, 1994). Situational factors refer to the particular combination of psychological and contextual factors that exist in a specific pain situation such as understanding about the pain source, expectations for obtaining pain relief from a certain treatment, ability to use simple coping strategies, perceived control during a painful situation, and

relevance or significance of the pain (McGrath, 1994). These factors represent a unique interaction between the person experiencing pain and the context in which the pain is experienced especially during the childhood.

Situational factors vary extensively, not only for different people experiencing similar pain frame reference, but also for a particular person experiencing the same kind of pain reference at different times. Even though the pain source remains constant, the specific combinations of situational factors are unique for each occurrence of pain. These extremely variable factors, along with behavioral and emotional factors can explain why the same pain level would evoke different pains reference in the same person at different times or in different people at the same time. Similarly, these factors may explain why the analgesic effectiveness of proven interventions varies in different times (McGrath, 1994). Therefore, it is essential to evaluate these factors as secondary causes of pain, as well as the primary pain etiology.

1.4.4. Coping in relation to gender and age

Coping represents a dynamic person-environment interaction, it is never a unique episode, but is assessed moment by moment. Factors such as the context of dealing with the conflict, represents a specific moment of the episode, in order to build an entire mechanism against the conflict. Studies describe the inter and intra-individual aspects of coping in regard to situational determinants differ from one another in accordance to the context (Frydenberg, 2004).

Gender and age-related differences are very important when building a coping assessment tool. Girls are more inclined to turn to others, think hopefully, and resort to tension-releasing strategies, and they are more likely to do this as they get older (Frydenberg & Lewis, 2000). There is some evidence that functional coping decreases with age and emotional coping increases with age. Thus, older adolescents generally use more tension-reducing strategies than do younger adolescents (Frydenberg & Lewis, 1999b). A study conducted between 1991 and 1995 (Frydenberg & Lewis, 2000) tracked 168 students on three occasions over a 5-year period. It found that where both boys and girls remain relatively stable in their inability to cope between the years spanning age

12 to 14, boys report much the same low level 2 years later, although the girls report significantly increase in ability to cope by the time they are 16. Therefore, boys remain relatively stable in their declared inability to cope between age 12 and 16 whereas girls show significant trend in having more difficulty in coping by the time they are 16 and are more likely to declare their helplessness than the boys. It is the use of tension-reducing strategies, self-blame, and keeping to self that are the most concern (Frydenberg & Lewis, 2000).

Additionally there are thoughts in coping, such as between the ages of 13 to 15, which prove to be downturns or what might be called critical points. For example, the involvement in social action, turning to spiritual support, and the use of psychical recreation decrease in use between the ages of 12 and 14. Thus by the age of 16 it is important to equip young people with the strategies to cope (Frydenberg & Lewis, 2000).

Adolescents coping resources are important underpinning for wellbeing. We know, for example, that there is a positive relationship between the use of productive coping and the reduced use of non-productive coping in relationship to self-efficacy (i.e., belief in one's capacity to cope with situations), academic wellbeing, and achievements (Frydenberg & Lewis, 1999b).

Another important factor for coping is the relationship between family conflict and adjustment, especially when children/adolescents have a positive perception of their family environment. In a study in 2007 (Vashchenko, Lambidoni, & Brody, 2007) described children using external strategies such as blaming others and acting out. Females relied more on social support, whereas males tended to avoid the problem or engaged in blaming (Hamid, Yue, & Leung, 2003). Santiago & Wadsworth (2009) reported that family conflict is strongly associated with internalizing symptoms for adolescents under high levels of economic related stress.

Age effect reflects development change in cognitive abilities to use more complex cognitive strategies in dealing with stress (Hample, 2007). Older adolescents use coping strategies such as problem solving, accepting responsibility, self-controlling, and social support in dealing with problems more frequently than younger adolescents. They are more likely to try alternative

strategies in their repertoire of coping skills when the initial coping strategy is not effective (Williams & McGillicuddle-De Lisis, 1999).

Ebata and Moos (1994) and Gelhaar et.al. (2007) found that active coping was prominent among early adolescents and internal coping which is used on cognitive-reflective processes emphasizing appraisal of the situation and possible solution was highest among late adolescents. Zimmer-Gembeck and Lockea (2007) reported a positive association between coping such as active, avoidance, and wishful thinking and age. Other studies reported that coping remain somewhat stable over time and no age differences was found (Mullis & Chapman, 2000; Kirchner et.al., 2010).

1.5. Developing coping measurement scales: An evaluation framework

In general, researchers of coping mechanisms agree that the study of coping is fundamental to an understanding of how stress affects people, for better or for worse. Although, it has proven difficult to document unequivocally, researchers of coping argue that how people deal with stress can reduce or amplify the effects or adverse life events and conditions, not just on emotional distress and short-term functioning, but also long-term, on the development of physical and mental health or disorder (Skinner, et. al., 2003).

At the same time, however, little consensus can be found about conceptualizing or measuring the central constructs in the field, namely, ways of coping. In the broadest sense, ways of coping are the basic categories used to classify how people cope. They capture the ways people actually respond to stress, such as through seeking help, rumination, problem solving, denial, or cognitive restructuring. Categories describe what is happening on the ground during coping episodes, that is, “specific coping responses: the behaviors, cognitions, and perceptions in which people engage when actually contending with their life-problems” (Pearlin & Schooler, 1978, p.5). They are the mechanism through which coping have short-term effects on the resolution of the stressor as well as long-term effects on mental and physical wellbeing. The empirical examination

of coping categories distinguishes research on coping from closely related work on stress, adaptation, risk, resilience, and competence.

From outside the field, it may seem surprising that such fundamental distinctions were not agreed on long ago. However, from within the field, the problem is quite obvious. Compas and colleagues (2001) summarized the current state of affairs in a recent review, “In spite of the clear need to distinguish among the dimensions or subtypes of coping, there had been little consensus regarding the dimensions or categories that best discriminate among different coping strategies in childhood and adolescence” (p. 5). Even a cursory survey of categories used in coping scales and coding systems underscores this conclusion.

It seems as if the identification of core categories of coping has taken place almost by default, on the basis of the categories that happen to be included in the measures used most frequently. Lack of consensus about core categories has further slowed progress in the field. The most obvious problem is the difficulty in comparing and cumulating results from different investigations. Owing to the fact that the number and kinds of coping categories are specific to studies, it requires an item-by-item of subscale to decide whether findings are comparable. This makes it practically impossible to aggregate findings relevant to the same stressor and domain, much less to compare results of different stressors or domains. Nor is it possible to compare the use of different ways of coping across age, impeding the study of the development of coping.

In their review, Compas et.al. (2001) concluded that “there has been little consistency in the application of these various subtypes of coping across different measures and studies…. leading to considerable difficulty in developing a cohesive picture of structure of coping in childhood and adolescence” (p. 5). The same holds true for adulthood and old age.

Confusion about core constructs is also a barrier to the accumulation of knowledge needed for explanatory and intervention efforts (Sandler, Wolchik, MacKinnon, Ayers, & Roosa, 1997). For example, if the antecedents or consequences of a certain way of coping differ from study to study, it becomes difficult to determine whether inconsistencies represent the differential

functioning of the coping method across time or domains or whether they reflect differences in the definition of that method of coping across studies.

Table 2: Coping scales derived from the Ways of Coping Checklist (WOCC) from eight analysis (Skinner et.al., 2003)

Study	WOCC	Categories
Folkman & Lazarus (1980)	Original	Problem focused Emotion focused
Aldwin et.al. (1980)	Original	Problem Focused Wishful thinking Growth Minimize threat Seeks social support Blame self Mixed (Both problem & emotion focused coping)
Parker et.al. (1996)	Modified	General coping Specific coping - Direct coping - Suppression
Vitaliano et.al. (1985)	Revised	Problem focused Emotion focused - wishful thinking - distancing - emphasizing the positive - self blame - tension reduction - self-isolation Mixed - seeking social support
Folkman et.al. (1986)	Revised	Confrontive coping Distancing Self-controlling Seeking social support Accepting responsibility Escape-avoidance Planful problem solving Positive reappraisal
Aldwin & Revenson (1987)	Revised	Escapism Cautiousness Instrumental action Minimization Support mobilization Self-blame Negotiation Seeking meaning
Dunkel-Schetter et.al., (1992)	Cancer version	Seek and use social support Cognitive escape-avoidance Distancing Focus on the positive Behavioral escape-avoidance

Note: Coping Definition. Adopted from "Searching for the structure of coping: A Review and Critique of Category Systems for classifying ways of coping," by E.A. Skinner, K. Edge, J. Altman, & H. Sherwood, 2003, *Psychological Bulletin* 129 (2), p. 221. Copyright 2003 by the American Psychological Association. Adopted with permission

Disagreement about core coping categories has interfered with methodological

progress as well. New questionnaire assessments, representing an enormous investment of effort, appear regularly. However, at the present time it is difficult to evaluate the clarity and comprehensiveness of the sets of categories on which each of these questionnaire assessments is based. The development of alternatives to questionnaire methods presents an even greater challenge. Despite the call for methods that more easily capture the dynamics of coping, the complexity implied by dozens of ways of coping makes it difficult to organize observational coding schemes, code open-ended narratives, or develop succinct daily assessment.

The fundamental problem in identifying core categories is that “coping” is not a specific behavior that can be unequivocally observed or a specific belief that can be reliably reported. Rather, it is an organizational construct used to encompass the myriad of actions used by individual to deal with stressful experiences. As pointed out by Pearlin and Schooler (1978), “Coping, in sum, is certainly not a unidimensional behavior. It functions at a number of levels and is attained by a plethora of behaviors, cognitions, and perceptions” (p. 7-8).

There are countless changing real-time responses that individuals use in dealing with specific stressful transactions, such as “I wore my lucky socks the day of the surgery” or “I read everything I could find about it.” In operational terms, these are captured by self-reports or actual coping behaviors or by real-time observations. At the highest level are sets of basic adaptive processes that intervene between stress and its physiological, social, and psychological outcomes. This level refers to coping as a “strategy of adaptation” (White, 1974), serving larger evolutionary functions, such as continuing to secure adequate information about the environment or escaping from a potentially dangerous transaction.

The central notion is that the structure of coping spans the conceptual space between instances of coping and adaptive processes. Hence, the critical problem for the field is to construct a complete and coherent set of categories at an intermediate level that organizes innumerable situation-specific highly personal responses with respect to their functions in mediating the effects of stress.

1.6. Children's experience with medical procedural pain

Health care professionals strive to provide medical treatment while avoiding any undue pain and suffering by the patient. Despite these underlying goals, children's procedural pain because of medical treatments has historically been undertreated and under-recognized (Chambliss & Anand, 1997). Failure to adequately treat children's pain is likely due to beliefs that young children, and particularly infants, do not perceive as much pain as adults because of their immature nervous systems and that untreated pain would not have any adverse long-term consequences (Schechter, Berde & Yaster, 2007). Contrary to such views, it has been demonstrated that infant and children experience pain in a similar manner to adults (Porter, Wolf, Gold, Lotsoff, & Miller, 1997). Furthermore, high levels of pain in children may have significant neurophysiological effects (Ruda et.al., 2000; Taddio et.al., 1997) as well as psychological effects on them (Eland, 1993).

Inadequately managed pain in children can also have detrimental psychological consequences, which can in turn lead to higher levels of pain during medical treatments. For example, emotional factors such as elevated anxiety, distress, anger, and low mood, can increase the child's pain perception (McGarth, 1994) and render subsequent medical procedures and pain management more difficult (Frank et.al., 1995). Moreover, a large-scale early study found that as many as one-third of children who undergo medical procedures for diagnosis of treatment showed some evidence of subsequent psychological adjustment problems (Davies, Butler, & Goldstein, 1972). In addition, reports of fear and pain experienced during medical procedures in childhood and predictive of fear and pain during medical procedures, as well as avoidance of medical care, during young adulthood (Pate, Blount, Cohen, & Smith, 1996).

Children are fearful of experiencing pain during medical procedures and may associate going to the doctor's office with needle procedures (von Baeyer & Spagrud, 2007). Fear is defined as "an immediate alarm reaction and an intense psychological response (Albano, Causey, Carter, 2000; McMurtry et. al, 2015). Children's medical experiences can have both short and long term consequences on their mental and physical health (McMurtry et.al., 2015;

Taddio et.al., 2009; Pillai-Ridell et.al., 2015). For example, when the fear and pain associated with needle procedures are not addressed, individuals may be at long-term risk of experiencing increased procedure-related pain, developing needle phobia, and not adhering to vaccination recommendations (Taddio et.al., 2009; Taddio, Ipp, Thivakaran, et.al., 2012). There is a general consensus that providing accurate medical information may result in more positive emotional and physical outcomes for children (Jaaniste, Hayes, von Baeyer, 2007). Children may benefit from an evidence-based educational program on the general medical procedures that occur commonly throughout childhood (e.g., vaccinations, and check-ups during well-child visits).

A failed pain treatment can lead to a feeling of loss of control, and it then becomes impossible to find adequate coping strategies. The negative emotional feelings, i.e., fear and distress, often take over the situation (Lu et.al. 2007). Instead, children need to find coping strategies to manage and reduce harmful and long-standing negative effects (von Baeyer et.al. 2004). These coping strategies also need to be tailored to the children's individual development and cognitive ability (Piaget & Inhelder, 1969).

The long-standing effects of under-treated pain are delayed healing, psychosocial problems and recurrent pain syndromes (Coulling, 2007). This explains why adequate pain management is essential in the context of pain care (Coulling, 2007). An earlier survey on wound pain discovered that nurses tend to focus on the healing processes rather than on the overall pain experience of the procedure. However, children need a holistic approach to pain care (Briggs et.al., 2002). The children's own need and the ability of the environment to respond to their requests are essential in pain management. This includes the children receiving support from their parents (Power et.al., 2007). Also, the children's expression being interpreted (Vaartio et.al., 2008). Children's ability to express pain is dependent on their involuntary and voluntary response to the pain stimuli. A response with a reflexive escape, facial grimaces and cry often transmits emotional reactions to the observer. In contrast, a controlled pain expression without behavioral reactions from children does not generate emotional reactions for the observer (Craig et.al., 2010). In addition, there are several pain assessment tools to measure pain in children (RCN, 2009). Pain

assessment should always be followed up with treatment strategies for the children. Pain management often involves the children receiving a combination of pharmacological and non-pharmacological treatments in wound care (Howard et.al., 2008).

There is a lack of knowledge about pain management in conjunction with procedural pain care (Weinberg et.al., 2000, Summer et.al., 2007). Children need coping strategies to help them manage trauma procedural pain care without lasting negative memories (Blount et.al., 2006; Ulman, et.al., 2006). The children's coping strategies in this context are voluntary or involuntary, and unmanageable situations often lead to involuntary and negative coping skills that worsen the situation. Lazarus stated that if someone really wants to study coping styles, it might help to examine these styles interactively with the situational context and consider central personality traits. In other words, emotions are best as narratives (Lazarus, 2006).

Most knowledge of procedural pain in children is taken from short procedures such as vaccinations. Different coping strategies are thereby required to help the children master longer procedures (Landolt et.al., 2002). To be more precise, the suggestion here is that more knowledge of children's experiences of longer procedures increases the opportunity of administering sufficient procedural pain management. The main goals of pain management in pediatric nursing are to give individualized care, to involve the children in decision-making and, finally, to bring about holistic nursing as defined by the comfort theory (Kolcaba & DiMarco, 2005). This theory describes holistic nursing in four contexts: physical, psych-spiritual, environmental, and sociocultural. The physical context of comfort concerns the bodily sensations, the psycho-spiritual context of comfort concerns the internal consciousness of the self, the environmental context of comfort describes the external surroundings and finally, the sociocultural context of comfort defines the interpersonal, family and societal relationships (March & McCormack, 2009). Holistic nursing strives to give comfort, which involves relief, ease and transcendence in health care that is stressful. To achieve relief, children must have their specific needs met and to achieve ease, children require a state of restfulness or satisfaction. The basic assumption of the comfort theory is that all humans have a holistic response to

complex stimuli such as wound care (Kolcaba, 1994). Consequently, further research is needed in interventions that enhance holistic comfort in children (Kolcaba & DiMarco, 2005).

1.7. Descriptive results of children 'coping strategies' with pain and chronic disease

Many children and adolescents experience pain that can last for hours or even days (Goodman & McGrath, 1991). However, the coping strategies for pain differ between children that have chronic disease and healthy children with only a short episode of pain. Based on the theory of Lazarus (1984) researchers found a strategy to approach children with chronic disease and consequently pain, by introducing a questionnaire measuring coping strategies. Keefe et.al., (1990) designed the Coping Strategies Questionnaires on which researchers base their findings. On the first group, I will introduce the studies of coping strategies with healthy children. Curry and Russ (1985) observed and interviewed children undergoing dental procedure and Ritchie et.al., 1990 observed children receiving injections. Both studies found that children used coping strategies such as information and support seeking, distraction, denial, avoidance, and calming self-talk.

Furthermore, Altshuler and Ruble (1989) assessed children's coping in response to hypothetical vignettes involving dental injections. The responses were coded into categories such as a- coping (e.g. positive self-talking, talking with someone), b- catastrophizing (e.g. escape/avoidance, anxious anticipation), c- approach (e.g. information seeking), and d- emotional manipulation (e.g. behavioral or cognitive distraction, escape, denial). Alex and Richie (1992) from interviewing children 7-11 years olds after surgery, found that they used strategies such as distraction, thought stopping, and inactivity. Branson and colleagues (Branson, et.al., 1990; Bennett-Branson & Craig, 1993) found that children commonly used medication, diversion, reappraisal, relaxation, calming oneself, and restricting movement to deal with postoperative pain. Children's pain coping strategies have been found to relate to pain intensity, emotions distress, and functional disability (Gil et.al., 1991). Brophy and Ericson (1990) found negative self-statements were related to higher levels

of anxiety among children undergoing surgery. Bennett-Branson and Craig (1993) discovered that behavioral coping strategies were related to less pain while catastrophizing strategies were related to more pain and poorer physical recovery among children undergoing surgery.

In severe cases, such as children diagnosed with cancer, their coping strategies were classified into three groups: a) affective: self-talk, crying; b) acceptance: sleeping, being quiet, and c) active: asking questions, talking to parents, daydreaming (Weekes & Savedra, 1988). Gil et.al. (1991) findings were adopted by Varni et.al. (1996), theory that involved the study of children with Sickle Cell Disease. They concluded three order scores: a) coping attempts (i.e. diverting attention, reinterpret pain, ignoring pain sensation, calming self-statement, increasing behavioral activity); b) negative thinking (i.e. catastrophizing, fear self-statement, anger self-statement, isolation); and c) passive adherence (i.e. resting, taking fluids, praying and coping, heat/cold massage).

Regarding the second group of studies with children coping with recurrent pain such as arthritis and headache, the results had very intensive scores compared to the first group. Varni et.al. (1996) found that:

a) Cognitive self-instruction and seeking social support were related to increased depression or anxiety, and parent-rated adjustment problems.
b) Striving to rest and being alone was related to higher pain intensity and poorer adjustment (increased depression and anxiety, lower self-esteem)
c) Cognitive refocusing is mainly related to less pain and depression
d) Problem solving/self-efficacy was related to less depression and state of anxiety and higher self-esteem
e) Coping measure appears to have heterogeneous content making interpretation of these correlations somewhat difficult.

A Dutch study of adolescents with headaches found that palliative, avoidance, and depressive coping strategies were related to higher pain intensity. Whereas depressive coping strategy were related to longer headache duration (van den Bree et.al., 1990). According to Gill et.al. 1991 study among children with Sickle Cell Disease, coping attempts were related to more pain intensity and functional

disability. Meanwhile, negative self-statement is considered to have higher levels due to anxiety among children undergoing surgery (Brophy & Erikson, 1990). Furthermore, behavioral coping strategies are related to less pain while catastrophizing strategies are attributed to more pain and poorer physical recovery among children undergoing surgery (Brophy & Erikson, 1990).

In Reid et al. (1995) study, lower levels of avoidance in response to diabetes-related stressors were associated with better academic adjustment and lower levels of (self-reported) depression. The use of approach as a coping strategy was not productive among these outcomes. Similar results were found by other studies. Avoidant behavior and ventilating one's feelings are related to poorer social adjustment (Grey et.al., 1991), and poor adherence to treatment (Hanson et.al., 1989).

Analogue findings appeared in studies involving children with other chronic diseases. In (Röder & Boekaerts, 1994) study, both children who did not approach and those who reacted emotionally in relation to an asthma attack (i.e. vented their feelings by crying, shouting, kicking) had more behavioral and emotional problems, as reported by their parents. Among children with sickle cells disease (Gil et.al., 1991), higher levels of 'passive adherence' (such as resting and hoping) in response to pain-related stressors was associated with a reduction in household, academic, and social activities. Tyc et.al. (1995) identified two subgroups of children (6-18 years) with cancer on the basis of the severity of self-reported coping efficacy and distress. The coping strategies which the subgroups of 'successful coppers' used most frequently to deal with nausea were 'problem-solving' and 'social support seeking'. Finally, Ebata and Moos' (1994) study among adolescents with rheumatoid arthritis also proved that avoidant strategies (except seeking alternative rewards) coincide with high levels of depression and anxiety.

Interestingly, the latter authors provided evidence that approach (such as positive reappraisal and problem-solving) and seeking alternative rewards are related to higher levels of self-worth and happiness. These limited findings seem to underline the pattern found in adults, but more research is needed to draw a firm conclusion. Kager and Holden (1992) found that children with

diabetes who used more diverse or more frequent coping behaviors reported higher general self-worth and better peer relations (less loneliness, more social adequacy, and higher peer status). In line with these findings, Rudolph et.al (1995) suggested that persons who have access to an extensive repertoire of coping strategies are more likely to cope effectively with stress. They argued that these children may be more flexible in the case of failure (if this strategy does not work, then I will try that one) and may thus, be in a better position to select their coping strategies in a context-sensitive way (if this is not appropriate in this situation, then I will try that one). But diversity does not always imply flexibility. Worchel et.al (1987) warned that the use of different, sometimes contradictory coping responses may be an indication that the child is unsuccessfully searching for a workable solution. They argued that it may be more adaptive to use only a few coping strategies well, than to have access to a wide range of coping strategies and use them erratically.

Lazarus and Folkman (1984) argued that there are no universally adaptive coping strategies that are suitable for all persons in all situations, reasoning that a question such as “which coping strategies are effective and which are not?’ can’t be answered and would better be replaced by ‘which coping strategies are effective for which individuals under what circumstances?’ Indeed, one can only say something about the effectiveness of a specific coping strategy only when that coping strategy has been utilized. Boekaerts (1996) maintained that it is necessary to have detailed information about the unique way in which children mentally represent a particular stressor, before the adequacy of their coping responses can be judged. More concretely, one needs to combine information about children’s perceptions of the characteristics of a specific stressor with the availability of specific coping strategies, and with their coping goal.

CHAPTER 2

ART THERAPY

2. INTRODUCTION TO ART THERAPY

2.1. Advantages of art Intervention with children undergoing medical treatment

Some experts argue that improved communication between health professionals and children or adolescents with chronic disease is needed (Claflin, 1991). Improvements to routine communication with health professionals and/or additional communication-based interventions may help children and adolescents in several ways. They may help children and their families to better understand, prepare for, and cope with the illness, the medical or surgery procedures they might undergo, their discharge from hospital and return to school and community, any relapses that may occur, and, in some cases, complications that might even put their life in danger. These children need honest communication that is appropriate to their needs and level of understanding (Diez et.al., 1997). Communication needs will vary across patients of different ages, preferences, types and stages of disease and treatment (Levenson, 1982). Young children in particular may be unable to understand or remember adult explanations, so it may be necessary to find alternative approaches to communicating with them about their treatment process (Eiser, 1986). Adolescents' coping skills may be already stretched by their passage through adolescence, making coping with chronic disease especially hard (Eiser, 1986).

Parents play an important role in meeting the communication needs of children with chronic disease. Parents are usually, though not always, gatekeepers for communication between health professionals and the ill child or adolescent. Communication with children and adolescents should be seen in context of the family and other support systems. This can make communicating with them about their disease and its treatment a more sensitive and complex task than with adult patients. A variety of different ways of enhancing communication with young chronic disease patients has been tried including play, art and storytelling, group therapy, and more formal education and rehabilitation

techniques. Advances in technology provide new opportunities for support using interactive multimedia (Bradlyn, 2003).

Baider (1989) implemented art therapy intervention to eight adolescents 15 – 20 years old who were diagnosed with cancer. Half of the patients were in remission at the time of the study or received ambulatory treatment. The group art therapy was developed in three months with weekly sessions of 1 hour and 50 minutes. The purposes of the study were to prepare the participants for support role in helping other patients cope with cancer and provide a healthy environment for discussion. The psychological, social and behavioral outcomes of the art intervention were measured utilizing two questionnaires, Brief Symptoms Inventory (BSI) and Global Severity Index (GSI).

Frick (1987) introduced play and storytelling intervention to children coping with cancer before the bone marrow aspiration (BMA). He introduced the art intervention to 15 children aged 3 -12 years old and hospitalized while waiting for the surgery. The aim of the intervention program was to reduce the level of anxiety of children awaiting the Bone Marrow Aspiration surgery. The State Anxiety Inventories (SAI) was used to measure the state of anxiety.

Favara-Scacco et.al (2001) used art therapy for 17 children aged between 6-14 years old and diagnosed with leukemia. These children were divided into two groups. Nine participants who were patients at the Department of Pediatric Hematology and Oncology of the University of Catana from September, 1997, to September, 1998, underwent art therapy and creativity intervention; whilst, eight participants whose first hospitalization was in September 1998 were not included in the art intervention program. The intervention fulfilled its goal, increasing the pain awareness in children coping with leukemia.

A few other attempts have been made to evaluate the role of art therapy among patients with chronic conditions (Broome et.al., 2001; Selyuchitsky, 2015; Miller, 2010; Scott, 2003; Foley, 1995). Ball (2002) introduced individual art therapy to 5 emotionally disturbed young children with attachment disorder in residential settings. The outcome of the intervention identified positive change/growth in children. Whereas, Gersch & Goncalves (2006) implemented art therapy to 10 years old children coping with family issues, grief, and various stressors. All the

5 participants showed remarkable improvement in coping feelings with their family situations. In 2000, Gunter used a qualitative study implementing individual art therapy to 4 children undergoing bone marrow surgery. After 2-3 sessions, the children gained confidence and reduced stress, while preparing for the surgery.

2.2. The origins of medical art intervention

Any expression of art can serve as a means to obtain pleasure, release tension, or express anger. There are two schools of thought: “Art as therapy” and “Art in therapy” both emerged in the 1930’s and 1940’s. Levick (1986) and Rubin (1984) claimed that “Art as therapy” represents various acts of creating something artistic (including painting, drawing, dancing, or music), introducing heal as a form of release tension, stress, anxiety, etc. This type of art “Art as Therapy” emerged with a small group of artists working with mental patients in hospitals and with problematic children in residential centers. As the years advanced, these artists were called art therapist.

Again, referring to Levick (1986) and Rubin (1984), “Art in Therapy” consists of a different group of art therapists, who examined drawings of children and adults with mental or emotional problems for clues about what the patients were consciously saying about themselves in order to elicit associations coming from their unconscious or hidden selves. In the present day, the two approaches seems to have merged into one qualified art therapy provided by many therapists and psychologists who believe that clients stand to profit more in case of a combination of both approaches.

Art therapy predates both psychology and psychiatry. Since early Paleolithic cave paintings, humans have used graphic depiction for psychological purposes. In cave paintings, they are believed to have served religious or mystical purposes, psychologically reading the hunter’s mind for successful hunting (Bradley, 1973). In some ways, these early paintings are made as symbolic offering of their hopes, wishes, and fears to the therapist in graphic, symbolic form and trusting that through this act will manifest an improved reality.

If art therapy is so “natural” and “easy”, why then, is there a profession devoted to its practice and perfection? A look at a commonly accepted definition of art therapy may provide clues. Art therapy is the use of art in a therapeutic setting for the psychological growth or improvement of humans (Packard, 1977). This definition specifies three critical criteria: (a) that it is the use of art, (b) in a therapeutic setting, (c) for human psychological growth or improvement. Controlled use practice of art therapy requires a category of people knowledgeable about the “how” of control and these are the individuals we call art therapists.

In the 19th century, it is the work of three individuals that paved the way for the use of art as a therapy today. The most commonly known is Sigmund Freud, who led the way to two of the major practices in art therapy: (a) the analysis of the art product as a major source of information about the client (Naumburg, 1965; p.3), and (b) the use of creative activity as healing, re-integrative force for the disorganized and disturbed mind (Packard, 1977).

Lesser known that Freud, but still influential during the 1800’ were the ideas of Lesare Lombroso and Hans Prinzhorn, each of whom wrote of the fascinating pictures of the mentally ill. Until their time, artwork of mentally ill patients was disregarded as meaningless scribbles and configurations and more expressions of their abhorrent behavior. For Prinzhorn (1972), however, they were eruptions of a universal creative urge counteracting the autistic tendencies toward isolation of schizophrenic personalities.

In 1897, in Vienna, Franz Cizek (Wilhelm, 1936) opened the Juvenile Art Class where instruction was designed to allow children to grow, flourish, and mature through creative art activity according to their own innate laws of development. As the first person to insist on creative capacity as the basis for art instruction, Cizek’s ideas were most influential on Lowenfeld’s (1947) own beliefs in the value of creative art activity for the healthy psychological growth and development of the child and the need for the therapist/teacher to provide the right supportive environment to allow this natural development process to occur.

By the mid-twentieth century a movement to utilize the art product as an indicator of the psychological and intellectual status of the individual had begun.

Florence Goodenough (1926) published her monograph on “The Measure of Intelligence” in Drawings; Rose Alshuler and Laberta Hatwick (1947) published a two-volume work on the meaning of graphic form in the art of preschoolers; Viktor Lowenfield (1947) first published seminal work on developmental stages in children’s art; and Karen Machover (1950) published an extensive study on how the personality correlates with human figure drawing. Also, by the middle of the twentieth century Adrian Hill had coined the term “art therapy” as a description for his work with tuberculosis patients in a sanitarium; John Levy in 1986, was among the first to use art in child psychotherapy, and Madeline Rambert (1949), a French psychiatrist, pioneered the use of puppetry in therapy. Thus, by the 1940’s, the essential theoretical foundations and treatment practices necessary for the beginning of a profession called art therapy were in existence.

The scene was now set for Margaret Naumburg (1965), who became, perhaps, the most important pioneer in the profession. Naumburg devoted an analytical approach to art therapy, stemming from the theories of Freud that stressed the release of the unconscious mind through the use of spontaneous art expression. As the years passed, she concluded that this form of spontaneous art expression was also basic to psychotherapeutic treatment (Levick, 1983, p.1). She labeled her approach “Analytic Oriented Art Therapy”, emphasizing the communication and transference between patient and therapist expressed in pictures and images. In this form of therapy, the patient sat at a table or stood at an easel and painted, drew, or modeled. After the work was done, the patient was encouraged to “free associate” about the work in order to discover himself or herself in symbolic significance.

The therapist provided neither rejection, nor criticism of the work or its interpretation; rather the patient was helped to understand what was happening and how to deal with it. As visual symbols more often escape censoring than do verbal expressions, each drawings or painting is viewed as an immediate communication with the unconscious. In 1947, Naumburg published a study on the use of spontaneous art therapy with behavior problem children and through her prolific writing, teaching, and lecturing throughout the country, established a core of disciples who have succeeded in bringing art therapy into nationwide

practice.

Edith Kramer (1959), the second major pioneer in art therapy, also had an art education background. Kramer, unlike Naumburg, placed the value of art therapy not so much on the symbolic communication of the product, as on the very act of creating art as a healing act itself. In Kramer's view, the therapist's primary function is to create an atmosphere alive with qualities essential to art creation. Through the creative act, the patient is able to graphically pictorialize inner sensations, desires, etc., and experience feelings, which will become satisfactory and desired substitutes for their earlier more destructive feelings.

To Kramer, the art therapist's role is "to assist the process of sublimation, and act of integration and synthesis which is performed by the ego, wherein the peculiar fusion between the unconscious and conscious, which we call art is reached" (Kramer, 1958; p.28). From 1950 to 1959, Kramer conducted an art therapy program at the Witwyck School for Boys in New York City, on which she wrote her first book in 1958 "Art Therapy in a Children's Community". This book, along with others written by her, writings by Margaret Naumburg "The Bulletin of Art Therapy" later retitled "The American Journal of Art Therapy" published by Elinor Ulman, beginning in 1961, and the journal Art Psychotherapy, first published in 1973, became the major sources of spreading the word on art therapy.

2.3. What are the major ethical principles of art therapy?

Relationship between artwork and verbal communication

When using artwork (an "unfiltered" form of communication), it should be treated as "symbolic speech" (Naumburg, 1965) and given all due consideration and protection just as any other form of speech.

Confidentiality: When a person enters a therapeutic relationship, he or she not only shares intimate thoughts and feelings with the counselor but may also reveal material that has never been told before. When clients reveal private information, they typically assume this material will not be shared with others

(Smith-Bell & Winslade, 1995). Everstine and colleagues (1980) asked who should have access to confidential information and what would happen to that information if it was revealed. These questions are important to consider when one is thinking about including actual artwork or photographs or artwork in a client's record. Because artwork done in the therapeutic setting often depicts childhood memories, dreams, and expressions of sexual and aggressive content, the counselor has a particular responsibility to decide which of the pieces are seen by others, even those who are part of a treatment team.

Documentation

This type of settings dictates how documentation is done. Certain institutional policies and procedures may present problems as to how one records a clients' artwork. They also raise the issue of ownership of the artwork. Some policies may require that the artwork itself be part of the client's record. This problem happens especially when the counselor photographs the clients' artwork and places them in the client's record. This is time consuming, expensive, and also puts at risk the confidentiality clause, because the client's record can be seen by other members of the institution and even discussed among them. Simply stated, artwork prepared in a counseling section is not the same as the one done outside therapy, which might have been intended for a more general audience.

Ownership

The type of setting in which the counselor works may dictate ownership of the artwork. The agency or institution may require that visual documentation be maintained as a part of the client's record. Policy may state that this is to be accomplished through photographs, slides, or by keeping the actual drawings or paintings in the client's record. Spring, (1994) stated that the ownership of the artwork should be discussed before the therapy begins, when the consent form is signed.

Use of art in research, publication and displays

This ethical issue is related to the privacy of the sessions even after they are over. Various therapists or researchers tend to publish artwork, or photographs done by their clients while being part of the therapy as part of a research study. Levy (1986) stated that our professional ethics are that the patients' healing comes first, because the patient is the most important factor, while the publishing articles using the patient's work comes next. This problem can be resolved by using a statement signed at the beginning of the therapy with the client, to gain the permission and make public the artwork. Some clients become more interested in the work and leave aside the therapy and the process of healing. Despite the complication during the sessions, if the artwork is published it should solely be for professional presentations.

Use of art by therapists who have trainings in art therapy

Art therapy seems to be a very easy profession as the center is the client's drawing. Any well-trained counselor should be able to talk with a client about the piece of art brought into the session, because the art is used as one would draw a dream or other personal experiences. The experience and training in art therapy is very efficient and gives enough confidence to infuse the process of art with verbal communication.

2.4. Descriptive results of researches implementing art therapy with children coping with chronic disease

Attempts to understand the emotions and improve communications with hospitalized children are very few; the above-mentioned are one of the most reveling conclusions on this category. Wischner (1952) used drawings with children diagnosed with stuttering disorder. He claimed that stuttering is a form of communication that usually occurs only in social interaction varying on the age, society pressure and the degree of stutterer who initializes these pressures and make them part of himself. Johnson (1967) suggested that one of the significant difference between fluent children and stuttering ones is not the amount or the type of non-fluency, but the label attached to it. Wischner (1952)

defined a slight difference with the adult stutterer, claiming their expression to be more distinguished than that of the children's.

Such results influenced researchers to use art therapy as an instrument of healing. Hiltebrand (2000) and Rosner & Ilusorio (1995) implemented art therapy for physically ill clients to manifest the pain, prognosis, and the emotions, as well as some benefits for the disease. Such manifestation made a correlation between the psychological and physiological states (Crown 1989; Tate 1989). Tate (1989) discovered that terminally ill patients while using art therapy use spirals to present death and suicidal thoughts. Bach (1966) and Perkins (1977) continued the work by implementing art therapy with terminally ill children who included windows in the eaves of the house while drawing. The Swiss folklore describes the death of a person, as their soul flying away through the window, although the children participating in the study were not aware of this story (Malchiodi, 1999a).

Symbols found in the drawings makes possible generalizing a unique vocabulary for interpretation of the pictures and understanding the root of the problem the client is manifesting. Edwards (1993) worked with HIV/AIDS patients who were newly diagnosed, administering art therapy. Besides the initial shock, they fill the drawings with universal symbols such as sun, rainbow, family, etc. The most frequent symbol was the flower, expressing the "compensatory self-symbol" (p.327). Additionally, Minar (2000) states that patients often create images of the "hurter" and the "healer." The "hurter" models relate mostly to the illness itself or the clients' feelings of the disease, often using symbols such as volcanic eruptions, sunset or forest. The symbol of the "healer" is usually visualized with the portrait of God, family, friends, karma, etc. Sometimes the "healer" and the "hurter" emerge on the same painting.

2.5. Person Picking an Apple from the Tree (PPAT)

Gantt and Tabone (1998) developed the Person Picking an Apple from the Tree (PPAT) based on the Formal Elements Art Therapy Scale (FEATS) assessment. The PPAT is a single picture assessment, which was standardized

by Gantt (1990, 2000). Both the rating scale and the assessment have evolved over the past ten years. Munley (2002) conducted a pilot study to determine if children with Attention Deficit Hyperactive Disorder (ADHD) reasoned differently to art directives compared to children with no learning or behavioral problems. Using a population of young boys, between 6-11 years of age, Munley (2002) compared the PPATs of boys diagnosed with ADHD to a matched reference comparative group that had known behavioral or learning difficulties. Five raters blind to the hypothesis used the FEATS to rate the drawings. He found that three FEATS categories significantly predicted artists in the AD/HD group: color, prominence, details of objects and environment, and line quality. Afterwards, he selected the PPAT/FEATS because the media could easily be manipulated by children diagnosed with AD/HD. Additionally, Munley (2002) felt that FEATS provides a valid and reliable rating method to evaluate the global characteristics of the drawing. Munley (2002) concluded that there is a strong relationship between the rating scales and AD/HD symptoms, and it required only one drawing.

The participants of the study were 5 children between ages 5 and 12, who were not being medicated for their AD/HD diagnosis. All participants came from a behavioral health system in a suburban Midwestern industrial town, in the United States of America (USA). All of them were Caucasian. The control population came from a Midwest urban parochial school and contained 13 males with no known behavioral or learning problems. They ranged in age from 5 to 10 years. None of the matched pairs was more than 6 months apart in age according to Munley (2002). The raters were five in number, with a strong interest in art and extensive experience with children. They included an Architect, a nurse, an art historian, an interior designer, and a businessman (four women and one man). The raters were blind to the study's hypothesis. Receiving two hours of training, the raters then rated the 10 drawings for the study using FEATS. The rating of the drawings took just under two hours. Munley (2002) stated that a strong inter-rater correlation was confirmed. The observation revealed that when making the drawings, the boys in the AD/HD group were easily distracted and impulsive in their physical movements. The boys in the reference comparative group were more focused and took a longer

amount of time to complete the drawing. The results of the study were limited by the small sample size and lack of a representative sample.

The Draw a Person Picking an Apple from a Tree is an art therapy drawing evaluation from the Formal elements of Art therapy Scale (FEATS). In this evaluation, the children are asked to draw a picture of a person picking an apple from an apple tree. The FEATS scoring system rates 14 variable (promotion of color, color fit, implied energy, space, integration, logic, problem-solving, realism, developmental level, details of objects, line quality, person, rotation, and preservation) in each drawing on a scale of 0-5, with each providing an evaluation of the child's coping abilities and resourcefulness.

Prominence of Color refers to the way in which color is applied to objects or area of the drawing. If color is used only for outlining a form or object, then a rater will score the art as having a "1" on this scale. If the entire surface is covered with color, the rater will score "5" on this scale. This scale can be used for every type of drawing that uses colors, and include scribbles, such as the one used by Cane (1999). Artistic convention of drawing permits some of the paper to show in drawings. In painting, the convention is to cover the entire canvas. One would first have to conduct a pilot study on a sample from a wide range of people in order to see if this scale has any utility for studying paintings. If the majority of paintings in the pilot study were rated as 4s and 5s, the scale would not have been needed to make fine discrimination on this variable.

Color fit measures the way in which conventional or realistic color is used. One could apply this scale to any drawings or painting in which a relatively realistic object is included. However, it is not useful for abstract or nonrepresentational art. If a researcher is working with a drawing of a specific object, he or she can modify the FEATS discretion to the raters to denote the appropriate colors or color range. If a person names a particular object or objects as being in the picture, then the researcher should make notations of it and include that information with the drawing so that the raters may make their judgment. It is important that low scores on this scale not be considered pathological. The expressive use of color in and of itself occurs in several different groups, as

does the random use of color. Many examples of unusual color fit are found in the work of great artists.

Implied energy measures the degree of effort it would take the rater to do that same drawing. The raters usually put themselves in the artists place and consider the energy one would expend to make the drawing. The “least amount of energy possible” is rated of “1”, an average amount is rated of “3”, and an “excessive amount” is rated of “5”. The scale is easily used to scribbles, abstracts, or nonrepresentational art.

Space is an easy to use scale for all types of two dimensional arts. It is the only variable that can be measured on a true scale (has the properties to permit mathematical operations). The scale assigns points to less than 25%, between 25% and 49%, between 50% and 74%, between 75% and 99% and 100% of the space used. For every detailed measurement, finer levels can be taken, but these gradations are sufficient for most studies.

Integration is a broad application to all types of art. Certainly, it is easier to apply this scale to a composition that consist of two or more objects or people. Presumably, one should be able to apply the criterion to a nonrepresentational composition. However, discerning the individual “parts” of such a composition might prove difficult if raters cannot agree on the specific parts as opposed to “part of parts”. Therefore, acceptable inter-rater reliability may be difficult to obtain. Researchers should conduct a pilot study with a varied sample of nonrepresentational art to determine if raters agree on the measurement of this particular variable before proceeding to use it in a larger study.

Logic deals with the inclusion of bizarre or illogical elements that are not part of the requested response. The scale distinguishes between intentionally humorous or satirical items and those items that seem to have no reason for being in the picture. For example, in one of our PPAT’s, the artist drew the person sitting on the branch of the tree using a pickaxe on an apple computer. This type of drawing has several elements that are satirical rather than bizarre or illogical. Like the scale of Integration, this one should be applicable to many types of drawings and paintings.

Realism is used with drawings for which there is a directive to make a specific object or when the artist describes part of the drawing as being a specific object. Thus, if a person had been asked to make a scribble and declared the image to be “a dog”, then the researcher would need to relay that to the raters. This variable may also be associated with education and artistic training so, it is imperative that investigators consider this in their research design.

Problem-solving measures the degree to which the artists show the drawing of a person actually getting the apple out of the tree. It was a serendipitous result of the directive for the PPAT. Other attempts have been made to find a new drawing that might serve as an alternative for the PPAT in order to have an equivalence of “form A” and the “form B”.

Developmental level has a broader stage, overpassing the scale ranges “0” to “5”. Those who are studying children’s drawings may want to expand the number of points for the whole numbers or to retain our numbers and define specific half-points. Either way, it would be important to have a more finely graded scale to use with the children’s drawings. However, we are not certain that this scale will have much utility like using an aggregate of several of the more specific ones such as Implied Energy, Space, or Details. While many art therapists can easily apply Lowenfeld’s stages (1939) in a general way to children’s art, it remains to be seen if this scale has discriminatory value with art done by adults. This scale does not relate specifically to a symptom in the four Axis I disorders, it was originally studied for.

Details of Objects and Environment is used when the directive requires identifiable objects, but not with abstracts or non-representative art. In the main, it measures whether the person simply followed the directions in a concrete fashion and only included the specific items in the directive, or added/embellished the initial stimulus to make a fuller picture. “Abundant and inventive details” are rated “5”.

Line Quality looks at the overall line quality and the degree of control that the artist presumably exercised. Raters are asked to “average” the lines in the drawing. Excessively “fluid or flowing lines” are rated “5” while lines that “appear to be drawn with the shaking hand” are rated “3”. One can use this scale with

any drawing in which colored pencils, markers, or other relatively fine-tipped media are used. However, the process of laying down color when painting or using pastels makes line quality difficult to judge.

Person asks for the degree to which the drawing meets the criteria. As we studied our archival pictures, we realized that there are several aspects of this variable in which we were interested but which this scale did not capture (such as gender, age, orientation of face, and clothing). To remedy this, the FEATS developed content scales (nominal or categorical scales) to capture this information. Those researchers who are working with drawings that routinely contain a person may want to add these nominal scales to their ratings (Gantt & Tabone, 1998, p. 47-51).

Rotation, preserved from the literature of the Bender-Gestalt Test (Lacks, 1984). However, in the art of very young children, neither variable is pathological. Rotation measures any items that deviates from an expected position (vertical or horizontal) or from a presented design one must copy. Trees, people (unless they are placed in an unusual position by virtue of the directive), and houses are the objects most likely to be treated this way.

Preservation is a repeated motor act such as making a short line over and over without seeming to be aware of doing so. There are other types of preservation but FEATS is interested in just one. On occasion, one might see preservation in nonrepresentational or abstract art. For those who study children or adults with organic mental disorders such as Alzheimer's and other dementing illnesses, this scale will be of special interest. Unlike the other scales, Preservation and Rotation do not seem to be normally distributed. It is our impression that scores of "1", "2", or "3" do not mean pathology in children.

The PPAT is a test qualified to serve the art therapist in two separate ways. Firstly, the test complies its main purpose as a diagnostic instrument and as a one session intervention (Implemented only once with the children and analyzed by the 14 variables). Secondly, the art therapist uses the test as a source of main therapeutic goal, by introducing the child to the main option of the test, picking the apple. Such are the only two studies using the second method for children coping with chronic disease. The PPAT, was introduced to

22 children with Asthma (Beebe, Gelfand, & Bender, 2010) between 7-18 years of age, these students are in a school located on the National Jewish Health campus. The students diagnosed with asthma required daily treatment and participated in 1 hour of art therapy session for 7 weeks. The study divided the children into two groups, the experimental group consisting of 11 participants and another 11 in the reference comparative group . Results changed immediately after the art therapy indicated a reduction in child-reported worry scores from the Pediatric Quality of Life Questionnaire; a reduction in the anxiety score, and improvements in the color, logic, and details scores from the FEATS in the intervention group compared to the reference comparative group. Results from this study established for the first time in a randomized clinical trial that a program of art therapy lowers anxiety and improves quality of life and self-concept in children with asthma. These results were striking, and benefits from the art therapy persisted even 6 months after treatment. The use of art therapy for children with severe, chronic asthma is clearly of benefit.

In continuity, FEATS served as an intervention for 10 children at the hospital diagnosed with Epilepsy (Strafstrom, Havlena, & Krezinsky, 2012). The study included 7-18 years old patients diagnosed with epilepsy from the pediatric neurology clinics at the University of Wisconsin Hospital and Clinics, for at least 6 months. After 1 hour of art therapy every week, the study showed that children with epilepsy lagged in artistic development. Therefore, art therapy focus group can provide a safe, nurturing environment for children and adolescents with epilepsy to explore and discuss their disorder with similarly affected peers, allowing the development of strong interpersonal bonds and enhancing long-term psychosocial functioning. The effects of the art therapy intervention were also measured from the Pain Coping Questionnaire and Coping Strategies Questionnaire.

Furthermore, Foley (1995) published her research describing the different scores measurement from administration of the PPAT to a group of 25 chronically ill hospitalized children in Ohio, United States (asthma, diabetes cystic fibrosis, and anemia) and 25 healthy children. Based on the six month of research gathering the drawings of children, the results were pretty as expected for the healthy children. They had higher scores in the PPAT test. The most

important and surprising discovery was the Problem-Solving FEATS variable. In the case of the healthy children, they included the person on a ladder or other reasonable type of support, or on the ground reaching the apple, but not able to grasp it. Contrary, the chronically ill hospitalized children revealed a new tendency, drawing the person either unable to get the apple, or the person having the apple in hand, but not showing the means at to how he/she got the apple. This difference is attributed to the learned helplessness the chronically ill children develop. They often have a loss of independence, which can lead to a sense of helplessness or ineffectiveness (Foley, 1995).

CHAPTER 3

THEORETICAL BACKGROUND

3. THEORETICAL BACKGROUND

3.1. Coping Theories

3.1.1. Coping and Stress cognitive appraisal theory

Lazarus and Folkman in 1984 found the best known and accepted definition of coping. Cognitive theory defines stress as a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being (Lazarus & Folkman, 1984, p.9).

The stress appraisal include two components: primary and secondly appraisal

- Primary appraisal refers to the stakes a person has in a certain encounter. The situation is perceived as being either irrelevant, being positive or stressful. These events classified as stressful can be further subdivided into categories of benefit, challenge, threat and harm/loss. A stress-relevant situation is appraised as challenging when it mobilizes physical and psychological activity involvement. While appraising the challenge, the person may see an opportunity to dare himself experiencing pleasant, exciting, and interesting situations. Thread occurs when the person is perceiving danger and is experienced when the person anticipates future harm or loss, related mainly in situation like physical injuries, pain or attacks. In case of a thread, the individual puts together the strength to master the situation faced by aiming for victory. Thread, concerns a coping capability toward a hurtful aspect of the environment. Differently, in harm/loss the individual instead of mastering the situation surrenders, becoming overwhelmed by feelings of helplessness. Beck's cognitive theory of anxiety and depression (Beck & Clark, 1988) is the fine line between the cognitive content in anxiety and the loss as its counterpart in depression.
- The second appraisal includes the resources to cope with the demands of stress. The individual evaluates his competences, social support, and

material, or other resources in order to readapt to the circumstances and to reestablish equilibrium between the person and the environment.

In continuity, Lazarus (1991) mentioned personal resources including commitments and beliefs. Commitments represent motivational structures such as personal goals and intentions that determine perceptions of situational stress relevance and the stakes at hand. Beliefs are personal antecedents of stress appraisal. They are convictions and expectations of being able to meet situational requirements. By using “generalized beliefs”, as opposed to situation-specific appraisal control, other factors are engaged such as locus control, general self-efficacy, trait anxiety, or self-esteem. Given a stressful situation, low dispositional control expectancies make people vulnerable to distress (Bandura, 1992).

Different ways of coping have been found to be more or less adaptive. Suls and Fletcher (1985) concluded that avoidant coping strategies seem to be more adaptive in the short term in case of adjustment illness, whereas, attentive-confrontative coping is more adaptive in the long term. It remains unclear, however, how the specific coping responses of a patient struggling with a disease can be classified into broader categories. Some researchers have come up with two basic dimensions such as instrumental, attentive, vigilant, or confrontative coping on the one hand, opposed to avoidant, palliative, and emotional coping on the other (Parker & Endler, 1996). The most well-known approach is the Lazarus and Folkman (1984), who discuss between the problem-focused and emotional-focused coping.

The problem-focused coping seeks to ameliorate the stress being caused by a given situation by identifying and making efforts to deal with the source of the problem. It may involve taking action to remove a stressor or to evade a threatening stimulus. For example, faking headache to avoid an injection. By effectively removing oneself from the threatening situation, one lowers the stress it induces. The goal of emotional-focused coping is to reduce the intensity of distressing emotions associated with stress that aims to make oneself feel better about the real or perceived threat or stressor without addressing the source of the stress. Emotion-focused coping often occurs when

problem-focused coping fails to reduce the stress in a situation or when the stressor is so great that the problem-focused coping has no real likelihood of helping. It can also come into play when one is dealing with a terminal illness or sudden death of a loved one. (Lazarus, 1966)

Charles Carver and his colleagues (1989) developed an instrument to measure coping responses based on a number of conceptual distinct methods of responding to stressful life events.

- Active coping involves taking steps to remove oneself from threatening situation.
- Planning involves generating strategies to cope with the stressor.
- Reinterpreting the stressor as a positive growth-oriented expression.
- Suppression of competing activities (i.e. putting other concerns aside until the stressor sufficiently subsides).
- Restraint coping (i.e. waiting for an opportunity to act affectively).
- Focusing on and venting of emotions such as expressing grief or “venting” anger.
- Humor while coping with the stressor.
- Mental or behavioral disengagement such as giving up trying to solve problems or reach a goal.
- Seeking social support can be either instrumental support like information and resources or emotional support such as sympathy and understanding.
- Turning to religion (i.e. putting the problem in God’s hands).
- Acceptance when the threat is accepted as unavoidable (terminal illness).

Meanwhile, Klauer and colleagues (1993) updated the theory by developing five coping strategies a) Seeking social integration, b) rumination, c) threat minimization, d) tuning to religion, and e) seeking information. Coping also has a temporal aspect. One can cope before stressful events take place, while it is happening (e.g., during the progress of a disease), or afterwards. Beehr and McGrath (1996) distinguished five situations that create a particular temporal context: a) preventive coping: long before the stressful event occurs, or might

occur, such as a smoker might quit well in time to avoid the risk of lung cancer; b) anticipatory coping: when the event is anticipated soon. For example, someone might take a tranquilizer while waiting for surgery; c) dynamic coping: while its ongoing such as diverting attention to reduce chronic pain; d) Reactive coping: after it has happened; for example, changing one's life after losing a limb; and e) residual coping: long afterward, by contending with long term effects, for example controlling one's instructive thoughts years after a traumatic accident has happened.

In 1984, Lazarus and Folkman affirmed that it requires cognitive changes and constant behavioral efforts to manage specific, internal and/or external demands evaluated as a burden or as something that exceeds the person's resources. They developed eight factors describing coping strategies of children with chronic disease.

Factor 1- Confrontation: This strategy corresponds to the offensive strategies for coping with the situation. These are the strategies in which the child presents attitude related to the stressing agent. They frequently present aggressive behaviors regarding people delivering care to them as a way to demonstrate their anger. (e.g. "I was mad at them, as they tied me up for the injection"). The strategies involved in confrontation do not always lead to positive results. Sometimes adolescents decide to do something that is not recommended by the health care practitioner, trying to find a solution to the problem, engaging in risky behaviors such as unfounded beliefs, drinking teas, praying, and leaving behind traditional treatments (e.g. "someone told my mom that this tea makes miracles for diabetes").

Factor 2- Distancing: Different from confrontation strategies, the distancing strategy corresponds to defensive strategies in which the individual avoids the threat in an effort to change the situation. Denying the fact of their illness to themselves and not considering what is said by other people is a strategy used by the adolescents aimed at ignoring the disease. (e.g. "If someone says that I have diabetes, I can lie as nobody will control my insulin shots).

Factor 3- Self-control: Regards the person's effort in trying to control emotions when facing stressful stimuli. Adolescents try to control their emotions, keeping

their feelings to themselves. Having self-control also means not doing anything quickly or following the first impulse. For instance, as suggestions about treatment for someone are received, adolescents can think about it and make a decision about what should be done later (e.g. “I don’t like when people say things over and over again, what I am expected to do”).

Factor 4- Social support: This is a coping strategy that takes into account the support found in people and the environment. It is a positive psychosocial factor that helps adolescents to cope with the unwanted effects of stress and their response to the disease. The social support strategy presents three different aspects. These include a) social support to find solution; b) emotional support by friends and family members; c) professional support. As professional help is sought, adolescents search for education and treatment for the disease, as well as emotional support to better cope with problems related to chronic disease (e.g. “I have to remember when to take the medication, but then there is my family, doing everything for me”).

Factor 5- Accepting responsibilities: This is used when adolescents accept reality and commit to the process of coping with a stressing situation. Adolescents often feel responsible for triggering stressful situations and therefore face feelings of self-criticism and self-hate. However, these feelings can be motivating, stimulating them to cope with their problems in another way, keeping the disease under control and asking for autonomy.

Factor 6- Escape-avoidance: This consists of fantasizing about possible solutions for the problem without taking any actions to actually change them. We can describe it as an effort to escape and avoid the stressing stimulus. Many children and adolescents feel uncomfortable when being monitored or having their medication in public areas, in the presence of other people, which awaken normal curiosity.

Factor 7- Problem-solving: This presumes appropriate planning to cope with stressing agents. Instead of avoiding it or distancing themselves from daily life, adolescents or children choose to solve the problem by changing their attitudes, making them able to cope with the pressure from people and the environment around them, decreasing or eliminating the stress-generating source. These

adolescents will think of an action plan and will search for means of executing it, especially if the solution to the situation brings a feeling of not being different from others and improves the control of the disease (e.g. “I have to control my food, but I am a normal person”)

Factor 8- Positive reappraisal: This is guided towards controlling emotions that regard sadness as re-interpretation, growth and personal change arising from a conflicting situation. When reappraising their situation, adolescents find a way to cope with their problem using their own means. They are able to change something within themselves, not losing faith when facing the difficulties they must go through, growing as a person. In addition, they notice they can help the people close to them who are going through similar problems.

The scales of coping based on the definition and theory of Lazarus and Folkman (1984) are divided in three groups: problem focused, emotional focused, and avoidance. Each one of them refers to a particular set of behaviors engaged at the moment of a stressful event. What makes each of these coping scales different from one another?

Problem-focused coping versus emotion-focused coping. Lazarus and Folkman (1984) made a theoretical distinction between problem-focused and emotion-focused coping strategies. Problem-focused coping refers to coping efforts that are directed at managing or changing a situation that is causing distress. For example, cognitive decision-making, or thinking about one’s choices and planning a way to resolve a problem, may be considered a problem-focused strategy. Emotion-focused coping refers to coping efforts directed towards the regulation of emotions or distress. An example of an emotion-focused coping strategy is positive cognitive restructuring, or thinking about a situation in a more positive way. Lazarus and Folkman (1984) would also classify non-constructive coping strategies such as self-blame or self-punishment as emotion-focused, as they are coping strategies which are directed inwards, rather than externally at the problem.

In essence, Lazarus and Folkman (1984) distinguished coping on the basis of function (i.e., coping efforts which function to change the situation or an individual’s reaction to the situation). This theoretical distinction has withstood

empirical testing in the child coping literature. For example, while examining children's coping with interpersonal and academic stressors Compas, Malcarne, and Fondacaro (1988) classified the coping strategies of the children and adolescents according to the distinction between emotion-focused coping and problem-focused coping. They found that problem-focused coping was negatively related to both mothers' reports and children's own reports of their behavioral and emotional problems, and that emotion-focused coping was positively related to children's maladjustments. In addition, they found that children and adolescents utilized more problem-focused coping when they perceived the stressor as controllable, rather than uncontrollable. The robustness of the distinction between emotion-focused coping and problem-focused coping has been demonstrated in several studies of school-aged children (Band & Weisz, 1988; Forsythe & Compas, 1987).

Approach coping versus avoidance coping. In contrast to Lazarus and Folkman (1984), Moos and his colleagues distinguished coping strategies on the basis of their focus, rather than their function (Billing and Moos, 1981; Ebata & Moos, 1991; Moos, 1993). The focus of approach coping is towards a stressor, whereas the focus of avoidant coping is away from a stressor (Ebata & Moos, 1991). Approach coping can be defined as the use of cognitive strategies to change the way one thinks about a problem, and the use of behavioral strategies to avoid a problem or to relieve tension by expressing one's emotions. For example, cognitive avoidance (i.e., attempts to avoid thinking about a stressor) or emotional discharge (i.e., expressing negative feelings) would both be considered forms of avoidant coping, because they focus an individual's attention away from the stressor (Ebata & Moos, 1991).

The theoretical distinction between approach and avoidance coping has also been found to be empirically viable in the child and adolescent coping literature. For example, Ebata and Moos (1991) asked healthy, rheumatic, depressed, and conduct disordered adolescents to identify the most important problem they had to cope with in the past year. After controlling for age, stressor severity, and challenge appraisal of the stressor, they found that healthy and rheumatic adolescents used more approach coping, whereas adolescents with conduct disorder and depression used more avoidance coping. Overall, they found that

the use of more approach coping and less avoidance coping was associated with better adjustment. In addition, Hubert, Jay, Saltoun, and Hayes (1988) found that children using approach coping during the preparatory stage of bone marrow aspirations showed less distress during the aspiration procedure, as well as during hospitalization. These findings are consistent with Roth and Cohen's (1986) review of approach-avoidance coping literature. They found that, except, for situations that were very extreme and personally threatening, approach-oriented coping strategies were more effective in resolving interpersonal difficulties and were associated with less long-term psychological distress.

Non-constructive coping. Critics have stated that the existing coping classification system that differentiate problem-focused coping from emotion-focused coping (Lazarus & Folkman, 1984), and approach coping from avoidance coping (Ebata & Moos, 1991) are too simplistic to capture the diversity and complexity of coping (Aldwin, 1994). Specifically, researchers have found that some coping strategies identified by children are non-constructive (e.g., Causey & Dubow, 1992; Dise-Lewis, 1988; Spirito et.al., 1991). Non-constructive coping refers to coping strategies that one may use in an attempt to relieve distress or to alter a problem, but that may actually be harmful in the long term. For example, coping strategies such as aggressive actions and worrying/rumination could be considered as being non-constructive.

Empirically, the categorization of coping strategies as non-constructive has been found to be viable. For example, Causey and Dubow (1992) found that negative cognition or worrying was positively related to self-reported anxiety in children coping with a bad grade or with peer conflicts. Dise-Lewis (1988) found that the use of aggression was positively related to self-reported anxiety, depression, and psychosomatic symptoms in a sample of adolescents. Thus, it appears that certain coping strategies do not fit the categories of problem-focused/emotion-focused coping or approach/avoidance coping, and may in fact be categorized as non-constructive coping strategies

3.1.2. Attribution Theory

Attribution theory (Kelley, 1972) is often used to predict behavioral and emotional responses to stressful events. The way in which individuals explain the causes of events, or attributions, is measured across three dimensions: a) internal/external (the degree to which an individual perceives that an event is caused by personal factors as opposed to environmental or other external factors; b) stable/unstable (the degree to which causes are attributed to enduring or transient factors, and c) global/specific (the degree to which causes are attributed to a variety of contexts versus specific situations) (Kelley, 1972).

In the pediatric literature, a number of authors have shown that the types of attributions parents make about the causes of their child's behavior, can, in part, explain the emotional and behavioral responses of parents toward the child (Joiner & Wagner, 1996). Assessing the child's attribution is also important. The helplessness (Abramson, Seligman, & Teasdale, 1978), and the hopelessness models (Abramson, Metalsky, & Alloy, 1989) posit that individuals who tend to make internal, stable, and global attributions for negative life events are at increased risk for depression when confronted with stressful life events.

Attribution theory suggests that in answering "why" questions, people primarily distinguish between internal (self) and external (outside of self) explanations, thereby determining the locus of causality for an event (Allport, 1979). Whether the cause of an event is seen as internal or external systematically influences people's subsequent behaviors, motivations, cognitions, and affect them (Weiner, 1985). Identifying the locus of causality has been at the core of attribution theory since its inception and has generated an extensive research stream in the field of organizational behavior (Martinko et.al., 2006). But the question emerges of whether the "internal" and "external" categories capture the entire conceptual space of this phenomenon. Attribution theory has mainly focused on the individual level of analysis and identified the antecedents and consequences of attributions to either the self or someone/something outside the self, neglecting any potential relational aspects of performance.

The nature of chronic illness is one that exerts a heavy physical and psychological impact on the patients. They have to endure various degrees of physical distress over a long period of time and thus assume a greater responsibility for the ongoing management of their particular illness. Children are prone to various psychological complications while their main focus is the physical condition. Waldron and Varni (1994) developed five psychological and social conflicts that children coping with chronic disease develop.

a- Anxiety is a common response to the uncertainty of the diagnosis and prognosis of chronic disease as well as to various aspects of treatment (American Psychiatric Association, 1994). A major medical crisis can be a contributing factor in the onset or exacerbation of an anxiety disorder (Prescott, 2006). Almost all anxiety disorders may be seen in critically ill children; children with comorbid physical illness show greater levels of emotional problems, more somatic complaints, and more functional impairment (Chavira, et.al., 2008).

b- Depression occurs in at least 25% of cases (DiMatteo, Lepper, Croghan, 2000). Childhood depression seems to be evident at earlier ages in successive cohorts and often occurs with comorbid disorders, increased risk for suicide, substance abuse, and behavioral problems (Hatherill, 2007). Anxiety and depression are often associated with each other and are more closely related to asthma (Harrison, 2002) where estimates of psychopathology in severe asthmatics range from 30 to 63% (Wamboldt, et.al., 2001). Psychological stress may follow screening for diabetes as it may induce or worsen hyperglycemia (Sridhar, 2007).

c- General Self-Esteem: During childhood and adolescents, the social interaction plays a great deal in their life. Popularity in school or among the peers is very important. Children begin to compare themselves with the others, but when the physical conditions are not similar to compare they tend to lose interest in social interaction. Coping is a means to help children respond to difficulties. Self-esteem is often related to coping skills; e.g. children with low self-esteem tend to develop poor coping skills, and those with positive self-esteem develop helpful coping

mechanisms. Some of these skills are grouped to produce non-affective mechanisms:

- Denial: ignoring the problem, or pretending that it does not exist. It is very common when children cope with unpleasant things such as not accepting the health problems.
- Anger: negative emotional response to an unpleasant situation that can result in a verbal/physical reaction or just hidden inside. Sometimes, anger can motivate them to speak out and act out in ways that asserts their ideas or needs. However, uncontrollable anger may lead to behaviors that pushes other children or family members away and brings excessive criticism.
- Acting out: Express strong feelings in a way that can be emotionally, verbally, or physically abusive. Although, acting out usually is thought of as negative behavior, this is because at times it may be an appropriate and important expression of anger.
- Taking risks: children who are overly protected because of their medical condition may grow up to feel that they are entitled to special treatment from others. If they do not get this special attention, they may become disappointed and angry. In turn, they may blame others for their bad feelings. It is very important to challenge children to do all they can for themselves.

d- Internalizing vs. externalizing behavioral problems: Internalizing behaviors are negative, problematic behaviors directed toward oneself. Children with internalizing behaviors have difficulties coping with negative emotions or stressful situations, so they direct their feelings inward. Internalizing behaviors include:

- Social withdrawal
- Feelings of loneliness or guilt
- Unexpected physical symptoms such as headaches, stomach aches, not due to medical conditions
- Not interacting with others
- Feeling unloved
- Feeling sad

- Irritability
- Fearfulness
- Sleeping and eating problems
- Difficulties concentrating

Unlike internalizing behaviors, the externalizing behaviors are directed toward others. They include:

- Physical aggression
- Destruction of things
- Bullying

Externalizing behaviors can be easily seen, but for the internalizing behaviors it's very difficult to identify them. The externalizing behaviors are more common for boys in school, as a fight for popularity.

The terms "externalizing behaviors problems" and "antisocial" are almost synonymous to each other. The externalizing construct includes hyperactivity, and there are some hyperactive children who are not antisocial, again illustrating the difference between the terms "externalizing" and "antisocial". The DSM-IV describes externalization construct as oppositional defiant disorder, which involves oppositional behaviors (negative, hostile, and defiant behavior), especially displayed by young children to their parents and teachers.

e- Autosuggestion behaviors vs. Catastrophizing thoughts: Children with chronic disease especially those who perceive a certain level of pain find two different strategies to cope with their predicament. The two strategies have extreme effects on the cognitive development of the child. On the first mechanism, the autosuggestion behaviors are positive interactions while dealing with pain. The child gathers the strength and leads himself or herself to decrease the level of pain till an inner comfort is achieved. Such cases are very rare as the mechanism requires very strong confidence and concentration. Sometimes, this strategy may cause problems as the child chooses not to pay attention to what his body is experiencing and living in a fantasy that might be derived from some other psychological problems. Opposed to autosuggestion, the catastrophizers are pain

expressions that maximize proximity, or solicit assistance or empathic response from others in a social environment. They increase the pain attention and the exaggerated display of pain behavior may become maladaptive by actually contributing to heightened pain experience.

3.2. Theoretical approaches to art therapy

3.2.1. Existential approach

Frankl (1963) developed the existential theory, which involved putting the individual in the center and encouraging him/her to find a meaning for his/her existence, or better give a meaning for the situation through finding personal freedom. Bugental (1987) claimed that the main idea of the theory is to empower the client to find the meaning of beginning to live authentically. Infused with the art therapy, the existential approach finds the meaning in the images. The interpretation is irrelevant as much as the artistic expression and creative process. The focus of the theory is to leave the client breath-free, and not find every detail put down on the paper as a characteristic in need of interpretation. Sometimes, details such as colors, line quality, or size are just an artistic expression coming from imagination, or previous experience.

3.2.2. Person Centered Approach

The person-centered therapy assists the client to achieve autonomy, spontaneity, and confidence (Rogers, 1969). This therapy has the same principles as the existential therapy, but takes in consideration the process of becoming better and not reparation. The therapy believes that people are capable of expressing rather than repressing emotions and feelings. People are always fighting for a new movement that can be helpful. Child-centered therapy facilitates a process where the therapist trusts the inner person to make a journey to self-explore and self-discover (Landreth & Sweeney, 1993). The therapy has two main principles:

a. Active and Empathetic "seeing"

Rogers (1969) described the active and empathic listening as the ability of the therapist to give full attention to the client and actively enhance the awareness of the person for being fully heard and deeply understood. Regarding the art therapy, the process of listening becomes more a process of communicating and being empathetic through "seeing". The therapist is fully attentive to what the client verbally expresses but the details of the artwork are also centered during the sessions. Art expressions add another dimension of communication and words that can't be consciously said. The therapist gains some treasures from the clients' experiences, not necessarily conscious, to fully understand them.

b. Acceptance

Carl Rogers (1969) suggested acceptance to be one of the most important priorities in the therapy. It consists of accepting the client unconditionally, no matter what the problem or difficulties are. The self-centered therapy offers a positive atmosphere in the sessions. The client is free to express whatever emotional, physical, or social situation is encountered without fearing the therapist's reaction. Natalic Rogers (1997) the daughter of Carl Rogers continued the work of her father for more than 40 years. She demonstrated that art expression is a powerful tool to achieve self-realization and self-actualization.

3.2.3. Solution-focused approach

De Shazer (1991) observed that art activities support the Solution-Focused Approach treatment because they are less threatening and support the partnership between the client and the therapist. Solution-focused therapy is a modality, which was developed out of brief therapy, whose primary focus is problem-solving. In solution-focused therapy, the emphasis is placed on finding solutions and strengthening what is working as opposed to finding problems in client's lives (Molinar & de Shazer, 1987). Solution-focused therapy is a goal-oriented modality, which emphasizes the client's role in being an expert on oneself. In other words, even though the client may not be consciously aware,

he/she already possesses the solutions to challenges he/she is facing in his/her life. According to Cooley (2001, p.21), solution-focused therapy carries eight basic assumptions:

1. All clients have inner strength even if they are not yet aware of them
2. If what you are doing works, keep it up! If not, try something else!
3. Problems are not omnipresent. Sometimes they just exist to a greater or lesser degree.
4. Big problems do not always require big solutions.
5. If something changes in one area, it will impact other areas.
6. The solution may not be directly related to the problem.
7. The student is the expert on his/her problem.
8. Change is inevitable.

True to its name, solution-focused therapy shifts the focus away from problems and onto solutions. One of the tools utilized by solution-focused therapists is finding exceptions to challenging behaviors. Utilizing this method, clients are able to begin the process of transforming problem-oriented language into solution-focused language (Cooley, 2009). It is also an occasional practice in solution-focused therapy for the counselor to take on a position of the "not knowing" thereby transposing the traditional roles of client and therapy.

In addition, various techniques employed in solution-focused therapy are easily adapted to fit with other therapeutic modalities, such as art therapy (Molinar & de Shazer, 1987; Nims, 2007). Art therapy can be used as a primary modality, or can be combined with client-oriented, cognitive/behavioral and solution-focused therapies. Art therapy can be used as a short-term therapeutic tool when working with young clients or children on a variety of issues.

Art has always been used by humans as a form of healing and self-expression (Malchiodi, 2007). Cultures around the worlds use art as a way of sharing experience and connecting with others. While the idea of using art for purposes of expression and healing is not new, utilizing art for specific forms of psychological assessment and therapy is a 20th century concept.

The solution-focused therapy theory has four main techniques:

a. Neutralizing resistance

In the solution-focused art therapy, the therapeutic relations starts with setting mutual goals, targeting the negative reactions and neutralizing the resistance. The client is encouraged to draw the problem (as the process of drawing won't be that hurtful as is talking and personal interaction) and then elaborate his/her feelings through finding strategies to repair this problem and achieve the final destination, the goal (Selekman, 1997).

b. Exception-finding questions

Selekman (1993) describes how often it happens to forget that things change and people lose track of their reaction. By seeing the problem as an entire set of details, it's quiet impossible to break the barriers and find solutions or in best cases, deal with it. The exception-finding question is a technique that encourages the client to break the problem into very small parts and deal with them individually. Usually the client, being unreasonable and vulnerable can't manage it by himself. The therapist provokes the client to answer questions related to the problem, with an exception, the questions are never the center of the problem.

c. The miracle question

De Shazer (1991) is credited for inventing the "miracle question", leading the client to imagine if they would wake up the next morning and find themselves to be symptoms-free. It is a hypothetical question that frees the client even for one moment from the burden of the problem and regenerate strategies of managing while picturing oneself as a healthy person. Portraying the miracle question through art work brings a sense of immediacy to this question and employs a language that fits the client's dominant problem-solving approach.

d. Facilitating change

O'Hanlon and Weiner-Davis (1989) believe that by using a problem-solving approach, the results manifested are: a) changing the "doing" of the situation perceived as problematic; b) changing the "viewing" of the situation perceived as problematic, and c) evoke resources, solutions, and strength to bring to the

problematic situation (p. 126-127). The therapists can reinforce change by using additional Solutions-Focused Strategies.

When facing any difficult situations, individuals can choose to cope with them or try to ignore them. It is apparent that people should cope with their situation rather than resist it, however this is not always easy, as some do not know how. Art therapy offers a wonderful opportunity to cope, fulfilling many of the elements mentioned in the theories above. The power to choose and be active, which art therapy provides, are crucial elements in order to help one cope. Rogers (1977) expresses the necessity of these elements: “Therapy is not a matter of doing something to the individual, or of inducing him to do something about himself. Instead, it is a matter of freeing him for normal growth and development or removing obstacles so that he can again move forward” (p.6).

PART II

ORIGINAL RESEARCH

CHAPTER 1

CONTEXT DESCRIPTION, PURPOSES OF THE STUDY, HYPOTHESIS, AND OBJECTIVES

1.1. Context description

The research was settled in the Hospital Santa Maria, Lisbon, Portugal. Hospital Santa Maria is one of the main hospital Centers in Portugal. It was officially inaugurated in 27 April 1953. At the very same year, in October, the building opened the doors to the Faculty of Medicine of the University of Lisbon. Up to date, the center counts 13 departments of service and 2722 total number of health care providers. The Consulta de Desenvolvimento Center (The Center of Development for children) is an outpatient center, offering multidisciplinary services such as medical, social, psychological, etc. Located on the same campus of the Hospital Santa Maria, the center offers assistance to parents with financial problems. Conveniently, parents bring children to have regular check ups and have free access to every service and activity the center organizes. The social workers and psychologists monthly evaluate the child's progress and inform the parents to attend classes or trainings appropriate to their situation.

Outpatient pediatric services are provided on the sixth floor at the Pediatric Departments of the Hospital Santa Maria. The center offers services to children with a chronic disease, referred from other units, in need of a regular treatment that doesn't require hospitalization, but demands a long medical procedure within a day, and in some cases the surveillance of a nurse. Children come early in the morning to have their breakfast prepared accordingly to their treatment. While the health care providers prepare the medical treatment, children and their parents unite in one environment called Sala das Actividades (the room of activities) supervised by two educators who invite children to participate in activities, games, or different projects during the time of the treatment.

Both centers offer separate psychological services. Although, the room's sign on the door 'Mental Health Services' worries parents to ask for the service. Thus, psychological services are mainly provided to children who have a cognitive or developmental impairment. In case of behavioral or psychological

problems, parents find it more suitable to ask for a private service. The majority of parents that can't financially support the private psychological service rely on the educational system (school, kindergarten, summer camps, etc.), and in family environment.

1.2. Purposes of the study

The purpose of the study was to explore art intervention as an effective treatment modality for children diagnosed with a chronic disease to generate new coping strategies while living with the chronic conditions. A need for more successful therapeutic techniques for this category of children is needed. The combination of the coping questionnaires measured a variety of strategies , the most performed are avoidance and emotional focus behaviors.

Change process research has been identified as crucial to the growth of art intervention therapy. This requires intervention research, which provide a rich description of the dynamics of each therapy session and is the key to discerned when, why and how changing moments occur in therapy (Helmeke & Sprenkle, 2000). The baseline and after intervention measures, provided data to validate the effectiveness of art therapy as a treatment modality for children with a chronic condition. A need for intervention research into the use of art therapy with children diagnosed with a chronic disease has emerged as a theme throughout the review of literature.

1.3. Hypothesis

1- Art therapy intervention (in form of Solution Focused Approach & PPAT) improves coping strategies in school age children and adolescents used to deal with chronic disease stressors and different types of pain, without inducing any cognitive or physical developmental impairment.

2- The dimensions and categories of coping strategies classified from two different coping questionnaires (PCQ & KidCope) provide equivalent results for modification/changes in coping (scales and subscales) strategies to inquiry the role of art intervention with school age children and adolescents.

3- School age children and adolescents undergoing chronic disease treatment engage actively in the art therapy intervention sessions, improving their communication skills and increasing the descriptive vocabulary of pain level.

1.4. Research Objectives

Researchers of coping generally agree that these strategies are fundamental for understanding how stress affects people for better and worse (Skinner et. al., 2003). Thus, it is worthwhile to study the development of coping mechanisms in order to evaluate children's adaptation to adverse situations. There are very few intervention studies designed to modify the children's coping mechanisms related to the chronic disease, as well as experiencing particular type of pain (Ryan-Wenger, 1996). The first objective of the study is *to test the effectiveness of the two such art therapy interventions*: Solution Focused Approach and Person Picking an Apple from a Tree (PPAT) assessment test. The intervention process aims to change/modify children's coping mechanisms while undergoing medical treatment, as well as to create an innovative process replicable in any hospital environment for children dealing with chronic disease.

However, there is a lack of consensus about categorizing the dimensions of coping process since the number and types of coping dimensions are created differently for each study (Compas, 2001). Consequently, this makes it practically impossible to aggregate findings of different studies relevant to the same stressor and domain. This conceptual problem leads to the second objective, which is to combine *two different coping questionnaires (Pain Coping Questionnaire and KidCope) and merge their outcomes into a goal-directed process*, and measure the effectiveness of the art therapy intervention.

Finally, children coping with a chronic disease undergo lots of challenges to learn to comply with the medical treatment and continuous hospital visits. Despite health care providers' struggle to avoid any sort of pain while providing medical services, procedural medical treatment hasn't been recognized (Chambliss & Anand, 1997). Failing to treat children's pain adequately has an impact on coping strategies and may have adverse long-term consequences

(Schester, Berde, & Yaster, 1993; Varni et. al., 1996). This leads to the third objective of the study, which is to *adequately measure the levels of pain in children suffering from chronic disease while undergoing the art therapy sessions.* For that purpose we will use the standardized assessment test Adolescents Pediatric Pain Questionnaire.

CHAPTER 2

METHODOLOGY

2. METHODOLOGY

2.1. Type of study

The research is a mixed quantitative and qualitative research. The Quantitative phase of the research is composed by a descriptive exploratory comparative intervention study with randomized allocation of art therapy intervention. The qualitative phase was composed by individual case studies. The design grasps the meaning associated to the chronic disease and "coping" through the art intervention. Two homogenous group of study participants (children 7-18 years old diagnosed with a chronic disease) are randomly divided into two separate groups. The randomization was successful, thus, the groups are the same in all aspects, both measured confounders and unmeasured factors. The intervention is implemented in one group, referred as the experimental group throughout the study, and non-treatment group, referred as the reference comparative group. The number of participants was limited due to the inclusions criterion. It became a difficult endeavor to select children 7-18 years old diagnosed with a chronic disease without any cognitive and physical impairment available to attend 7 continues art intervention sessions. Most of the cases had very severe symptoms, were hospitalized, and couldn't manage to be part of the study as their health conditions were very difficult.

The setting was at the Hospital Santa Maria, Lisbon, Portugal. Twelve children with chronic disease were randomized to an active art therapy or reference comparative group. Those in active group participated in 7 sessions of art intervention for 60 minutes. Sessions included specific art therapy tasks designed to encourage verbal expressions of pain and modify coping strategies such as problem solving in response to the emotional burden of chronic disease. Measures taken at the baseline, and after the final art therapy sessions included: Formal Elements of Art Therapy Scale applied to the Person Picking an Apple from the Tree assessment test, children version of Pain Coping Questionnaire, Adolescents Pediatric Pain Tool, and KidCope. The children assigned to the reference comparative group completed all evaluation at the same intervals as the children receiving art therapy but did not receive art

therapy intervention. The children from the comparative group continued their routine visits at the hospital. During this time, they were taking part actively in the hospital activities, same as the children in the experimental group.

2.2. Study participants

Inclusion criteria involved 7-18 years old children with the diagnosis of chronic disease, who were outpatients at the hospital Santa Maria, Lisbon, Portugal. Parental consent and participant assent was obtained in accordance with hospital review board requirement. Exclusion criteria included children with acute symptomatic seizure only, cognitive impairment that would preclude participation in sessions, or physical or psychological disorder that would prevent participation. Twelve children were divided in two groups of six. Each group had 3 boys and 3 girls with an average age of 13. All children were diagnosed since their early childhood with a chronic disease and continue clinical treatment ever since. None of the children had a condition of comorbidity.

2.3. Instruments

2.3.1. Adolescents Pediatric Pain Tool (APPT)

The Portuguese version of the test was generated in 2013 from a group of researchers in Coimbra (Luis Batalha, Ananda Fernandes, Ana Perdigao, Armando Olivier, Eufemia Jacob, Lucila Castanheira, Sara Seabra, Manuel Brito). The study itself was conducted in two phases during November 2010 and February 2012. In the first phase the study developers translated the questionnaire (APPT) in Portuguese, based on the methodology of Beaton, Bombardier, Guillemin, and Ferraz (2000). In the second phase was done a semantic cultural validation with children at the oncologic department. This piloting phase assured conceptual, semantic, and idiomatic equivalence with the original version. The conceptual equivalence refers to concepts the children

diagnosed with a chronic disease use and if they have the same significance in another cultural context. The semantic equivalence evaluates the equivalence of the words that might need grammatical elaboration. The idiomatic equivalence is related to the idiomatic expressions when they are literally translated, if they have the same meaning in another cultural context. They also asked the authorization to use the questionnaire adapted for a different culture. The participation of the children was voluntarily after having the parents consent. The original version was translated simultaneously in Portugal and Brazil, but from independent working groups. After confronting the two versions, the translated tests did have some differences coming from the cultural context. Reason why there are two different versions, the Portuguese and the Brazilian version. The Portuguese version was reviewed by three native Portuguese speakers, and fluent in English, with working experience with children (developing psychologist, a doctor, and an English professor). This version was also reviewed by two English native translators who are fluent in Portuguese. After the translating procedure the study came to a unique version.

The semantic validation was conducted with 24 children, 8-17 years old diagnosed with cancer at the Hospital do Dia and Serviço de Hemato-Oncologia. Every child was interviewed individually working with a colored paper. They exchanged verbally to generate mainly the a- vocabulary the children use more frequently about the pain; b- words they don't use to describe the pain, but they know the meaning; and c- words they don't know the meaning. The children were also encouraged to generate other words, they utilize when expressing pain. The questionnaire now can be used without any problem with any category of children who experience pain, no matter the level of it. The Portuguese version is a reliable instrument (Fernandes, Batalha, et.al., 2015)

The Adolescent Pediatric Pain Tool (APPT) is a multidimensional self-administered pain assessment tool. The APPT is used with children and adolescents to evaluate pain intensity, location, and quality (including sensory, temporal, affective, and evaluative). The APPT can be used with individuals experiencing pain for various reasons, such as sickle cell disease (SCD), postoperative pain, allergy testing, orthopedic, traumatic injury, and cancer.

Overall, APPT was considered to be helpful to make decisions about pain management. Two studies (Crandall et.al., 2005; Van Cleve et.al., 1996) suggested APPT should be incorporated into routine pain assessment of children. A major advantage of the APPT reported was its ability to indicate pain location and quality. It was important not only for identifying sites of pain in the body (Holzemer et.al., 1998) but also for quantifying the extensiveness or spatial distribution of pain in the body (Holzemer et.al., 1998; Jacob et.al., 2003). Furthermore, extensiveness of pain indicated in the test, it was useful in the evaluation of drug effects after administration (Jacob et.al., 2008). Also pain location was found to be useful in predicting the amount of analgesia a patient would need (Candrall et.al., 2005). The use of pain descriptors was clinically useful to gain a more comprehensive assessment of the different pain dimensions (affective, cognitive/sensorial, evaluative, and temporal). In addition, the pain descriptors may be used as outcomes for evaluating the effectiveness of pain management interventions (Jacob et.al., 2008). For example words such "uncontrollable" and "never goes away" indicate ineffectiveness of pain management (Jacob et.al., 2003). One study indicated the lack of clinically significant decrease in pain intensity (Jacob et.al., 2003), and recommended that dimensions such as pain location and pain quality were more informative for assessing effectiveness of pain management strategies

APPT was described as readily understood and completed (Gillies et.al., 1997). Only Crandall et.al. (Crandall et.al., 2002) reported on limitation of the APPT for clinicians use. The major limitation was that clinicians did not know about the APPT or found it was not readily available. Also, clinicians believed it was time consuming (Candrall et.al., 2005), although Savedra et.al. (1993) reported that the mean time to complete the APPT varied between 3.2 min and 6.4 min. APPT was used in children 7-18 years of age such as Granados & Jacobs (2009) reported that the young adults patients with sickle cell disease and adolescents and Holzemer et.al. (1998).

Scoring:

The Adolescent Pediatric Pain Tool (APPT) provides five subscale scores:

1. Number of pain sites as a measure of pain location from marks on a body outline.
2. Pain intensity measured by the Word Graphic Rating Scale (WGRS) and anchored by the words no pain, little, medium, large, and worst possible pain.
3. Number of pain quality descriptors, which yields percent scores for the sensory, affective, and evaluative subscales.
4. Number of temporal descriptors, which yields a percent temporal subscale.
5. Percent of total pain quality and temporal descriptors as a total subscale.

2.3.2. KidCope

The KidCope (Carona et.al., 2014; Spirito et.al. 1988) asks about a checklist 11 different types of coping strategies, using 1 or 2 questions per strategy for a total of 15 questions. The 11 strategies measured are: distraction (I did something like watch TV or played a game to forget it), social withdrawal (I stayed by myself), wishful thinking (I wished I could make things different), self-criticism (I blamed myself for causing the problem), blaming others (I blamed someone else for causing the problem), problem solving (I tried to fix the problem by thinking of answers), internalizing emotional regulation (I tried to calm myself down), externalizing emotional regulation (I yelled, screamed or got mad), cognitive restructuring (I tried to see the good side of things), social support (I tried to feel better by spending with others like family grownups, or friends), and resignation (I didn't do anything because the problem couldn't be fixed). Although Spirito et.al. (1994) had heuristically grouped the 10 strategies into three categories - namely, Active (cognitive restructuring, problem –solving, emotional regulation, and social support), avoidant (distraction, social withdrawal, resignation, and wishful thinking), and negative (self-criticism and blaming others), the authors recommended analyzing each strategy separately because the function of a particular coping strategy was believed to vary by situation. Youth are asked to indicate both how often a particular coping strategy was used (i.e. frequency) and how much it helped (i.e. efficacy). Frequency is assessed by asking youth whether they made use of each

strategy (yes/no); efficacy is assessed by asking youth to rate how helpful the strategy was on a 3-point scale: Not at all, A little, or A lot.

The measure has been used with a variety of populations, including chronically ill children and their siblings, adolescents pediatric patients, victims of physical and sexual abuse, victims of natural disasters, and normal children and adolescents (Donaldson et.al., 2000).

The Kidcope comprises three sections: first, children/adolescents are asked to briefly describe a common or health-related problem/stressor (the latest was latest) they had experienced during the last month; second they report the intensity of stress responses (in relation to the previously identified problem) within a 5-point Likert scale ranging from 1 (not at all) to 5 (very much), in terms of Anxiety (Did this situation make you feel nervous?), sadness (Did this situation make you feel sad?), and anger (Did this situation make you feel angry); third, children/adolescents are asked to rate each if the coping items accordingly to whether they used a given coping strategy (Frequency Scale; “Did you do this?; response scale: 0=”not at all” to 3= “a lot”).

Rating the efficacy can be considered separately or in combination when scoring the KidCope. The KidCope shows a test retest validity and concurrent validity (Spirito et.al., 1994).

The Portuguese version of the questionnaire was assured by University of Lisbon, Faculty of Psychology Professor Luisa Barros. In collaboration with the University of Coimbra and the Professor at the Faculdade de Psicologia e Ciências da Educação in Coimbra Dr. Carlos Carona (Carona et.al., 2014).

2.3.3. The Pain Coping Questionnaire (PCQ)

Previous investigations have reported associations between children’s use of coping strategies and psychosocial function (Gil, et. al., 1991), the quality of the contrast with the physicians (Gil, et.al., 1993), patient-reported pain, emotional problems, and the coping strategies used by their parents (Olson, et.al., 1993). Coping strategies in children with chronic pain have, until recently, been studied

primarily using measures developed for adults (Gil, et.al., 1993). The Coping Strategies Questionnaire (CSQ) by Rosenstiel and Keefe has been adapted for children (Varni, et.al., 1983). The PCQ evaluates 3 types of adaptive strategies based on 8 scales for 39 items (Reid, Gilbert, & McGrath, 1998):

- Approach (research for information, solving problems, ask for a social support, positive autosuggestion);
- Avoid the center of the problem (distracting behaviors, cognitive distractions);
- Avoid the center of the emotion (externalization/internalization) which are not regulated;

Each of the 39 items is evaluated based on the Likert scale of 5 point starting from 1 (never) to 5 (always). The estimated time to realize the questionnaire is 15 minutes. The instrument has also some limitations. It has been designated to improve adaptive strategies for the children who face chronic pain but these strategies are not effective in a long duration of time. Being chronic diseases they persist through all children's life and that is the one main reason why every strategy may change and be modified over the time to take the shape of the situation and the personality of the patient. The questionnaire is build to measure not only the pain generated from a health condition but also when the children get hurt, how do they react toward the pain. The pain is a general concept that doesn't only imply when the children have severe health conditions. The mild level of chronic pain can be sometimes very difficult to handle and cope. Children especially chose coping mechanisms related to their resistance to pain. Some children are very sensitive to pain and the coping procedure becomes very difficult.

To score the dimensions of the coping it's necessary to take the mean of the items that make up that subscale/dimension. For example, scoring Decision Making dimension would involve either taking the mean of the items or the total score of the four items that represent that dimension. Generally, it is easier to use the mean of the items on that dimension when scoring the instrument. In doing this we typically require score for the dimensions. Scoring for the three major factors of coping (is reached by taking the mean of the subscale scores for the subscale/dimensions that comprise that factor. The Portuguese version

of the questionnaire was authorized from the University of Lisbon, Faculty of Psychology Professor Luisa Barros.

2.3.4. Person Picking an Apple from the Tree (PPAT)

The Draw a Person Picking an Apple from a Tree is an art therapy drawing evaluation from the Formal elements of Art Therapy Scale (FEATS). In this evaluation, the children are asked to draw a picture of a person picking an apple from an apple tree. The FEATS scoring system rates 14 variable (promotion of color, color fit, implied energy, space, integration, logic, problem-solving, realism, developmental level, details of objects, line quality, person, rotation, preservation) in each drawing on a scale 0-5, with each providing an evaluation of the child's coping abilities and resourcefulness.

Person picking an apple from a tree (PPAT) task, the subject is instructed to "draw a person picking an apple from a tree", on a 12x18 inch white drawing paper using felt tipped markers of 12 colors. The PPAT assessment focuses on how people draw, as opposed to what the draw (Gantt & Tabone, 1998). The PPAT is analyzed using the Formal Elements Art therapy scale (FEATS), which utilizes 14 Likert scales, with scores ranging from 0 to 5, to asses graphic equivalents of certain psychiatric disorders. The FEATS includes a developmental scale and can be used for both adults and children.

In the table 3 there is a description of the 14 variable FEATS elements. Although, this study takes in account only the 'Problem Solving' variable as the main element that measures the coping strategies.

The FEATS developmental scale is a 5 point measure that places the drawing in a developmental age range category; rating of 0=no elements identified); 1= Scribbling stage, approximately 2 to 3 years old; 2=pre schematic, approximately 4 to 6 years old; 3= schematic, approximately 7 to 10 years old; 4= pseudo naturalistic, approximately 11 to 13 years old; and 5= Adolescent, approximately 14 to 18 years old.

Table 3: Descriptive table of the PPAT scoring features (Rollins, 2005)

Variables/ Score	1	2	3	4	5
Prominence of color	If colored only to the outlines of the object	If color used for outlining most of the objects	If 2 or more objects are colored	If color is used for outlining as well as filling the objects	If color is used to outline and fill the objects as well as the space around (ex., sky)
Color Fit	None of the colors related to the specific object	If only one color is used but used under the directions	Some colors (but not all) may be related to the task	If all the colors are used for the specific object appropriately	If all the colors are appropriate to the specific object as well as nuances
Energy	If the picture has no energy (person showing but no approach to the tree)	If the person has the apple in the hand but is not reaching up	If there are some action such as reaching out or up	If the person is on a ladder and reaching for an apple	If the person is running or leaping high
Space (Divide the paper in 4 quadrants)	If less than 25% for the entire picture	If approximately 25%	If approximately 50%	If approximately 75%	If 100% of the space used
Integration	Picture with no composition	Attempt to connect two elements	Attempt to connect 2 or 3 elements	Picture with a composition	Composition well-integrated and well-balanced
Logic	Extremely bizarre elements	One not bizarre element	If has a few bizarre elements but generally logical	Mainly logic but one bizarre element	No bizarre or illogical elements
Realism	Picture is a scribble	Realistic elements for the objects (A lollipop tree)	Confusing details of the objects (tree with more than 1 trunk)	A realistic tree and other images	All element realistic an in a 3 D trunk
Problem Solving	The person can't get the apple	If the person has an apple in hand but is not apparent how he/she got it	If the person is on a rock, box, ladder but not reaching the tree	Person near the ladder or rock or on the ground reaching the apple but not able to grasp	Person on a ladder, rock, ground reaching the tree with the apple in the hand
Developmental level	Scribbles	Circular, rectangular shapes for body with no proportion	Baseline and object s lined up	Objects with realistic sized and details	Artistic sophistication
Details of objects/ environment	The objects have one detail such as one line for the trunk and a round shape for a top	If a horizon line is added or no suggestion of grass	Horizon line and one or two additional details	Many additional details such as sun, clouds, trees, birds	Special details such as lake, decorates clothes, hairs etc.
Line Quality	Lines of different sizes or that appear to have gaps	Lines that are erratically drawn or drawn over and over	Lines under control but not fluid or flowing	Lines flowing down and straight	Lines which are quite fluid
Person	No detail to be identified as a person	Only face or hand or some simple shapes	A stick figure	A stick figure with facial features	The most realistic drawing a person with all body parts
Preservation	Repetition of lines all over the picture	If the repetition of elements most part of the drawing (Continues lines with no connection)	A moderate amount of preservation (Many little marks appear to be multiple stems on one apple)	Just one detail of repetition such as in one apple	No preservation at all
Rotation (Clockwise)	If the axis point to 3 or later	If the axis are 2 and 3 a clock	If the axis points 1 and 2 a clock	Axis points 12 and 1 a clock (or 11 a clock)	Vertical axis (Drawn from head to toe or the tree from top to bottom)

Note: The Formal Elements Art Therapy Scale: The rating manual. Adopted from "Tell me about it: Drawing as a communication tool for children with cancer," by J.A. Rollins, 2005, *Journal of Pediatric Oncology Nursing*, 22(4), p. 210. Copyright 2005 by Association of Pediatric Oncology Nurses. Adopted with permission.

To date, the PPAT has been studies mainly through the FEAT scoring system (Gantt & Tabone, 1998), which measures global/formal art elements that emphasizing the way people draw the PPAT more than the content of the draw.

However, it can be assumed that PPAT's symbolic content also contains valuable information about the individual who drew it. Rollins (2005) used the PPAT method to promote communication for children with cancer. The content symbolism in this study will be described to understand the children's reaction toward coping strategies. The SC-PPAT symbolic content rating system comprises nine Likert scales presented in the table 20. The scales range between 0 and 5 or 6. A zero score means that the relevant object is missing from the drawing. Each scale measures one of the three characteristics: tree, person or person-tree relationship. Each of the scores, rather than reflecting positive or negative connotation about the drawings, simply reflects the amount of each measure variable. For instance, a drawing with a score of 1 on the FEATS Space scale would not be considered worse than a drawing with a score of 4, just indicates that more space is used. In other words, the numbers used in the rating scales are used to quantify the contents of the drawings.

2.4. Study Design

2.4.1. Choosing the sample

The research ran a purposive sampling with participants from both centers Pediatric Department of the Hospital Santa Maria and the Centro de Desenvolvimento, Lisbon, Portugal. The selection was assisted from two educators and the nurse of the pediatric department. An email was previously sent to them elaborating the participants' requirement and the study design. The nurse prepared a list of children from both centers fulfilling the preconditions. Children had very different schedules at the hospital depending on their medical treatment. Such, educators discussed the conditions of the two centers. Children coming at the pediatric department have more time alone and the environment is quieter compared to the Consulta de Desenvolvimento, where the space is small and children have to go from one service room to another during their medical treatment.

Initially, the list of the children selected was 11 and the educators were

expecting two new arrivals at the hospital. Educators intermediate the connection with parents and the children. All parents selected for the study accepted to join the research at once, except of one case who was going to leave the country in three months. Under this condition we had to cross out one participant, remaining 10. At the same month, in the pediatric department, educators added two more patients interested to join the research. After having their approval for the participation, the children were randomly divided in two groups of seven. Before signing the parental consent, parents participated in a meeting assisted by educators, nurses, and the researcher, explaining the design of the study, the sessions of art therapy, and the ethical principals of the work. We prepared a consent informal letter describing the conditions and the principles of the participations (Appendix C). The parent had enough time to read and decide to sign the formal consent. As well, educators invited parents and the children to see the room of the art therapy sessions. Parents signed the formal consent and the children gave their assent to participate after spending a few minutes in the art intervention room in the presence of the researcher and their parent.

The study started in March 2015 to end in March 2016. After the list of participants was confirmed, both groups had 6 children participating in the study. Their visits at the hospital had a frequency of minimum 15 days and maximum 1 month. During the summertime, some of the parents took provisions to give the medical treatment in another hospital near their vacations location. Both experimental and comparative group started at the same time the study procedure. Only the children from the experimental group would undergo art intervention for seven sessions.

2.4.2. The process of the research

I met with each of the parent for two meeting, in the company of the main educator of the center. The first meeting was prior to the onset of therapy to discuss the specific of participation in the study, and to obtain the written consent. The second meeting occurred as part of the first session

(administering the questionnaires). In this session/meeting I administered a simple questionnaire with the parents gathering demographic information for each of the cases (refer to Appendix G). The participants had a chance to reflect on the process and give feedback to me or the educators/nurse regarding what they thought was helpful. The information provided from the survey with the parents was kept confident. The educators and nurses were familiar with the sessions' content, necessary material to use. The art intervention sessions were settled in the room at the Pediatric Department of the Hospital Santa Maria, in my presence and the children alone, except 1 case, the child required the presence of the parent for the first 2 sessions. .

The intervention design has the three following steps.

In the first step the 12 children individually, without the presence of their parents filled the three instruments at the day they scheduled the visit at the center. The first questionnaire was the Adolescents Pediatric Pain Tool. This instrument takes approximately 10 minutes. When children required more time, then the limit was prolonged based on their specific needs.

On the same day, after finishing the first instrument, the child had 15 minutes of break, staying in the room without contacting her parents. The room had various board games to relax and prepare for the next instrument.

The second implemented instrument was the Pain Coping Questionnaire**.** The estimated time to answer the questionnaire is 15 minutes. Again, if the child required more time, the limit was prolonged. The aim of the second questionnaire was to evaluate the children's coping behaviors and highlight the domains of coping strategies. After the second instrument, children had a break of 15 minutes.

After the break, children continued with the last questionnaire, KidCope. The estimated time for this instrument was 10 minutes. As mentioned for the previous two instruments, the time was optional. At the end of the first step, the children had 15 minutes of break and then were invited to draw in a blank paper the first thing that came to their mind.

The second step started with the art intervention sessions. The art interventions sessions would start only after all participants in both groups had accomplished

the first step of the research. There were seven sessions of art intervention (*refer to the art intervention sessions description*) only for the experimental group. Children would come at 8 am on the schedule visit day at the hospital, have their breakfast and before the medical treatment they would spend one-hour art intervention. The sessions were always scheduled at 9 am.

The third step included both groups of children together. The children underwent the same procedure as in the first step. After the children had finished the seventh session, on the next scheduled hospital visit they filled the questionnaires. At the same time children from the comparative group started to compile the same questionnaires.

2.5. Data Analysis

Data was analyzed on an ongoing basis throughout the process of art therapy intervention. Art images and observation of the art process were observed regarding to each participant's individual process and progress, as well as regarding to the progress of the sessions. The participant's progress to attribute different coping mechanisms and the effectiveness of the art intervention to increase children expressiveness regarding pain and chronic disease, were measured from the two questionnaires evaluating the coping mechanisms. For each child from the experimental group, the involvement in the sessions' activities was observed. One of the 4 scales identified as appropriate for use with children and of particular interest to this study is the scale 8, the Problem Solving Scale, which the art therapists found especially useful in understanding the children's coping abilities and resourcefulness (Councill, 1999). The Problem Solving scale measures whether or not and how the drawn person gets the apple out of the tree. It can be related to affect and reflect feeling of helplessness and coping ability. Considerations include: How effective is the solution for getting the apple out of the tree? Is the method used realistic? This scale includes data to measure the role of art therapy in changing coping mechanisms in children living with a chronic disease.

2.6. Data Collection

Data collected for this study included all art works produced during the art intervention sessions, written observation of the session, recording, and staff comments. All art-work were photographed at the end of the sessions. Written observations were completed for each participant after each session and included notes on the participant's process of art making, level of involvement in the process, significant interactions, association to their images, verbal exchange, and other activities performed during one hour session.

All clinical staff members included in the treatment program participated in an open discussion to provide their feedback on the program and art intervention with the following topic: How did art intervention fit into the overall treatment program? How did clients react to the art intervention? What was your overall impression about the implementation of group art intervention in this context? (Appendix H) Some hospital staff members had been very close to the participants in the experimental group, while others observed the process through hearing about art sessions and speaking with the parents of the participants.

For each of the children in experimental and comparative group, the information regarding their health condition and hospital schedule, was provided by the nurses and the educators form both centers. The information was issued with the permission of the Pediatric Department Director and acknowledgement of the Director of the Pediatric Outpatient Unit from the Pediatric Department of the Hospital Santa Maria. The information gathered from the questionnaires at the first phase of the study, served as a buffer for the art intervention sessions with the children in the experimental group.

During the seven sessions, through exchange communication with the children in the experimental group, they provided information regarding their family composition. The information gathered from parents was optional to their choice. Regarding the comparative group, data on their family situation was gathered during the questionnaire administration at the Consulta de Desenvolvimento.

2.7. Study ethical principles

1. The parents have to sign the formal consent before the child participation. Art therapist respect the rights of clients to make decisions and assist them in understanding the consequences of these decisions. When clients lack the capacity to provide informed consent, art therapist protect clients' interest by seeking permission from an appropriate third party. The art therapist is not allowed to enter into multiple relationships with clients, otherwise it risk exploitation or harm the client with whom the professional relationship exists. Art therapist strive to provide a safe, functional environment such as adequate light, access to water and fresh air, compliance with any other health and safety requirements, and provide information in advance is the client has any discomfit from the art material used in therapy.
2. The information shared in the art therapy sessions is confidential and won't be shared with the health care professionals Art therapist protect confidential information obtained from clients, through art work and/or conversation, in the context of the professional relationship while clients are in treatment and port-treatment. Before the therapy, the art therapist informs the clients of the limitations of confidentiality. They do not disclose confidential information for the purpose of consultation without the client's explicit consent unless there is reason to believe that the client or other people involved are in danger or their life security is threatened. When the client is a minor, the parents or a legal guardian should sign for the informed consent. The records are kept safe for a considerate amount of time consistent from the state, and institutional laws and regulations. Records are stored or disposed of in ways that maintain confidentiality.
3. The patients' work (pictures, art work, etc.) is confidential and will be present in the room only during the individual sessions. Their work can be public only after the sessions have finished and with the consent of the child and the parents. The clients' artwork is regarded as a form of protected information and the property of the client. The artwork may be

released to the client during the course of therapy and upon its termination, in accordance with therapeutic objectives and therapeutic benefit. The clients have to be immediately informed when their artwork is photographed or coped for a digital image or publications. The termination of the protected artwork ends as a result of the death of the client. The original artwork is released to relatives. If the client is a minor under guardianship and the art therapist determines that the child's artwork does not violate the confidentiality the child entrusted to the art therapist. Before the session the art therapist should provide a written informed consent separate including the claws regarding the clients artwork (AATA, 2011). Art therapist when participating in a research study should include in the written informed consent, the artwork will be displayed with the research assistants and the supervisors.

4. Participants and their parents can decide to abandon the participation at any moment and the information gained will be destroyed immediately. The participants don't have any obligation to continue their pursuit with the project unless they are feeling comfortable with the sessions. Children at the end of the session are asked whether they like to continue with the next session openly.
5. Parents and the health care professionals are not allowed to participate in the art intervention sessions. Their participation in the art room may put the child in a discomfort position explore free the drawings. Furthermore, the child may encounter difficulties bind with the art therapist and trust for the confidentiality of the information.
6. The discussions and information gained from the nurses, educators, and pediatricians about the children during the time of the research is confidential.
7. The research will respect the participants' anonymity. Children's name and their parents will be kept anonymous during and after the art intervention.

2.8. Art Therapy intervention procedure

The art intervention is designed in seven sessions, corresponding the structure of the humanistic approach. Implementing artwork with children coping with a chronic disease at the hospital Santa Maria, Lisbon, has three main directives. Firstly, referring to the Frankl (1963), the child is led to find a meaning for the every day activities he/she attends. The child is free to use the colors, organize the space of the paper, use his/her images to externalize emotions, memories, feelings, perceptions retrieved from the hospital experiences. Consequently, analyzing the drawings characteristics such as color intensity, color fit, line prominence, etc., becomes just an esthetical point of the intervention, whilst, verbal exchange becomes prominent. Followed by the second directive, fulfilling the need to express versus repressing emotions (Rogers, 1969). The child, through continues verbal exchange is encouraged to self-explore him/herself by posing questions, curiosities about the health conditions, body function, and pain relate coping strategies. Lastly, restricted by the child's health conditions, and distant time among visits at the hospital, De Shazer (1991) formulated Solution Focused Approach by precipitating the effect of the intervention. The child is offered to find immediate solutions and coping strategies by using drawings as an intermediate for verbal exchange.

2.9. Art intervention room

In hospital it becomes difficult venture to find a room that fits the requirement for the art intervention. From the beginning the only room available at the pediatric department was the "Sala das Actividades", hosting parents and children during the medical treatment, assisted by the department educators. The room was small and noisy. The presence of the television in the room distracted children from any activity they were doing. The walls were covered colors and artwork provided by children over the years. Toys and puzzles were spread all around the tables and the floor, easing the vigilance of the parents and the educators, but hampering the concentration one specific task. Nurses were continuously entering the room with vignettes and medications, puzzling chidren's

imagination, whose turn was it.

Assisted by the educators, we found the library space of the hospital unit as an optional space for the art intervention room. Differently from the first one, this room was filled with shelves and books. The tables had computers and a very small space to pose the papers or the other materials. After days of discussions, this option was ruled out due also to continued students of medicine accessing the space for their own research as well as very dark environment.

The third option, was also the settled art intervention space. The room was previously used as a yoga space for parents and health care providers. For mother then 6 months, the room has been pending any activities as the yoga teacher has not been available to assist further classes. With her permission we obtained the key of the room and furnished it with the necessary materials. In the middle of the room we settled a table with four chairs. On the white walls, I printed descriptive information on daily routines, schedules to remember taking the medication, and breathing exercises. The educators brought some books and other materials for any artwork such as plasticine, water, colors, papers, colored papers, etc. Sudden changes of the room in particular are unsettling for the children as well as for myself. Changes are undesirable but sometimes unavoidable (Malchiodi, 1999a). Children have special conditions and needs and the room has to complete the aim of the intervention. Art rooms are forbidden to contain sharp or potentially dangerous items such as knifes, big scissors, rope, needles, etc. It is very necessary for the children to have positive association with the room. From the beginning they are asked if they were willing to add something to the room to feel more comfortable. In one case, we had to change the chairs as one child had a problem with the left leg, and needed a smaller chair. Comments about the room may also be unconscious reference for the intervention, as the humanistic approach concretize, the client is the center of the intervention (Rogers, 1969).

However, the room may have very good conditions but lack the light or the space discreetness. This can sometimes be offset by their proximity to disturbance nearby from the photocopier, airplanes, or people walking or talking

in the corridor. These external impingements, can be disturbing to a greater or lesser extend depending on what is happening in the art room. Though, some rooms raise anxiety. Newly furnished and carpeted rooms make children fear to mess the room and suppress their need or will to play or express oneself (Malchiodi, 1999a). In the room at the hospital the environment was big enough for movements, walking even running around the table if tired of being sited, protected by noise and external distraction, as well as no carpet and with comfortable chairs for one hour of intervention.

2.10. Description of seven art intervention sessions

Each session of art intervention will have a specified goal to achieve, and for a better understanding it's going to have a specific "subject".

The first session's subject was "Expressions". The child is free to choose one of the chairs around the table (in most cases the children pick one chair and every session they sit on the same position as their comfort zone). On the table are posed white papers A4 size, 12 colors crayons (black, blue, red, yellow, light green, dark green orange, purple, brown, pink, grey, white), and a paper with six facial expressions (happy, sad, worried, tired, angry, surprised). The child is encouraged to name the facial expression and use the colors to paint each of the emotions. The colors on the face expressions serve as a personal legend for each of the child. Although, in the art intervention colors have specific interpretation, based on the theory of Frankl (1963), during the verbal exchange the color fit with the emotions is just a map to enhance the emotions awareness. Also from the theory of Varni and Waldroni (1994) externalizing is considered a crucial domain of coping strategies. The child is encouraged to share for each of the facial expression one episode of their personal life related to the chronic disease or pain.

Objectives:

1- Identify feelings with the facial expressions
2- Introduce "pain" and "chronic disease" as two main keywords of the

session

3- Create personalized color match in regard to the emotions.
4- Encourage the child to externalize personal experiences from everyday life.

Session Two is dedicated to “Me”. The child is encouraged to draw a self-portrait. On the table there are the same materials from the first sessions as well as the drawings. After the child has finished drawing the person, by using different colors spread in the table, the child has to put different colors for different parts of the body. Such as red for the head, blue the arm, yellow the neck, and black the lips and so on. The child is free to chose the colors without being imposed or suggested when asked. After this process is finished the child is led into a discussion to identify those parts of the body he/she feels pain or discomfort. In accordance with the instrumental measurement, this session is mainly related with the questionnaire Adolescent Pediatric Pain Tool. The child has already identified the pain in the body through the questionnaire and in this session by using the colors he/she can describe the pain related to the emotions from the first session.

By using the Miracle Questions (De Shazer, 1991) the child is led to a new drawing of a person differently from the first one. Now the person doesn’t have any pain, nor the chronic disease. The child has to project again the colors over the body of the new drawing and rearrange the emotions depending on how would a person with no pain and disease would feel. Furthermore, the child is encouraged to create a story for this person while identifying the emotions for each part of the body.

Objectives:

1- Locate the pain in different parts of the body
2- Identify emotions for the level of pain in different part of the body
3- Contribute to a different example of life and emotions when having no pain and chronic disease

The third session is called “If the pain/chronic disease was a person or object how would you draw it?” Selekman (1997) introduced the “Exception – finding questions” technique. He suggested breaking the problem into small particles to

deal with it, as usually children tend to avoid the problem seen from a rigid perspective. This question of the third session also neutralizes resistance to accept the real size or severity of the problem. By identifying the pain or the chronic disease itself as a person or an object it's easier to identify it's characteristics as well as the fears or emotions attached to it. Firstly the child is encouraged to describe how would he/she describe the pain/chronic disease as a person or an object, then using these images in the paper. As always the table has the white papers and the 12 colors. On the corner there are posed the drawings from the other sessions. Referring to the theory of Lazarus and Folkman (1984), at the end of the session the child is confronted with the object/person drawing. The child has to mention three of the drawing characteristics he/she dislikes the most and what are the coping strategies he/she uses to deal with the person/object such as: confront it, ask for help, escape, find other solutions, self control, etc.

Objectives:

1- Identify the characteristics of the pain or chronic disease into an extinction perspective, not attached to yourself
2- Identify the fears and emotions related to the pain and chronic disease
3- Break the problem into small parts to deal separately with each of them

The fourth session aims to detect "catastrophizing thoughts", which is also the subject. In continuity with the third session, based on the theory of Lazarus and Folkman (1984), the table differently from the other sessions, won't ask the child to draw but to pick and have a verbal exchange. On the table there are two papers with two columns. On the first paper there is a list of ten medical interventions the children undergo during the time at the hospital. On the second paper there is a list of seventeen coping behaviors retrieved from the other studies on children coping with a chronic disease.

1- Injections
2- Medications
3- Meeting with the doctor
4- Blood drawing
5- Hospitalization

6- Stay in bed for a long time
7- High fever
8- Headache
9- Tired on my arms and legs
10- Pain on my shoulders

The child has to rank them depending on the difficulty scale they experience more discomfort. The coping strategies are generated from the instruments ranking from a positive coping behavior to a less successful coping behavior. The coping strategies are as follows:

1- Talk to a friend or family member
2- Watch Television
3- Avoid to listen anything and stay in my room
4- Read a book
5- Continue to think about it all the time
6- Start to cry
7- Start to dislike myself
8- I ask for help
9- I feel angry
10- I like to take risks
11- I search for a new solution
12- Blame myself
13- Blame the others
14- Think positive that everything is going to be fine
15- I wished I didn't have this problem
16- I daydream I had another life, another identity
17- I know that I have to deal with this problem and I prepare myself

After reading the 17 coping behaviors the child has to link one health condition with one coping mechanism. This net created between the two groups aims to detect the catastrophising thoughts they have when facing these specific situations. Through verbal exchange the child will generate strategies to find positive coping strategies while dealing with health conditions. To make it easier for the child in the mid of the session, five card are going to be presented on the

table. Each one of them describes a positive coping strategy:

1- Sharing with someone very close
2- Meditate (count to 10)
3- Auto-suggestion (think positive “everything is going to be fine”)
4- Rationalize (this treatment is for my health, so I will feel better)
5- If necessary in case there is a religious family, the intervention will consider religious positive inhibition as a coping strategy to deal with the disease.

Again the generated cope strategies are extracted from the instruments and the theory of Lazarus and Folkman (1984), inviting the child to learn and accommodate these new mechanisms while dealing with pain (not only health related) and with health complications. At the end of the session the child will pick one card from the 5 positive coping strategies and take it home, to return it in the next session.

Objectives:

1- Identify the hospital interventions causing pain and discomfort
2- Identify the coping strategies the children select to deal with medical intervention
3- Generate new coping mechanisms to deal with the problem

Fifth session’s subject is “Pyramid of needs”. The child has to draw a pyramid and write on each of the scales of the pyramid one need or activity he/she like to attend but has not been possible due to the health condition and pain. Through a verbal exchange the child has to identify the activities very likely to attend and cherish. On the other part of the session the child is led free to draw whatever coming in mind.

Objectives:

1- Identify the list of activities the child wants to attend
2- Identify the emotions behind it
3- Free association presented in the drawings aroused by the frustration of a forbidden activity

Session six has the subject of “Drawing the Person Picking an Apple from the

Tree". The child is led to draw a person and an apple tree without mentioning the process of picking the apple. On the table there are white papers and 12 colors also the pyramid of needs from the last session. After drawing the person and the apple tree the child is encouraged to identify each of the apples with one of the needs retrieved from the pyramid of needs. Based on the scale of the pyramid the apples also will be positioned on the tree. Through the technique of finding questions, the child is asked to see the problem from another perspective now. O'Hanlon & Weiner – Davis (1989) introduced *Facilitating Changes* technique that evokes changes in the way we perceive the problems. The child is asked to identify only three of these needs that he/she believes are the most important and need a urgent intervention.

Objective:

1- Identify the problem from an exterior perspective
2- Ranking the needs on a scale from more urgent to less urgent
3- Identifying the priorities

Session seven is called "Person Picking an Apple from the Tree". On the last session the children are asked to draw a person picking an apple from the tree. This time differently from the other sessions, the person has to pick the apple. Based on the FEATS principles the drawings underwent the process of analyzing the 14 variables of the test. The children will use the three apples selected from the sixth session to pose them the tree and this time is encouraged to generate strategies to find a positive solution to pick the apple. From the theory of Varni and Waldron (1994) approximation to the problem was one of the best approaches to cope with the chronic disease. In this session the child is led to see the problem from another point of view. The problem will remain to be the same but there are other solutions that can satisfy needs as well as being close to the activity the child likes. For instance, usually children like to play football but due to their health conditions they can't run, or have pain in their legs, etc. As football might be very important for the child, there are other ways to stay close to the game. Writing about sport, have interest on the medical sport, etc. "Pick the apple". This is the aim of the PPAT test itself to lead the child toward the process of picking. The child is lead to divide the first

apple in four pieces to see, the same as the activity or need he/she has. By this technique, the problem has different perspectives, and looks easier to be resolved. As mentioned before for the football player, there are different points of view attached to a certain aspect.

Objectives:

1- Identifying the aim “Picking the apple”
2- Breaking the problem into small particles to release the burden
3- Encouraging to make decisions and face the problem

Table 4: Outline of art activities during the art intervention session with children of the experimental group

	Session #1	Session #2	Session # 3	Session #4	Session # 5	Session # 6	Session # 7
Title	Expressions	Me – Draw Self	“If the pain was an object/person how would you draw it?”	Catastrophizing	Pyramid of Needs	Presenting “PPAT”	Drawing PPAT
Materials	Paper Format A4, Pencil Crayons 12 colors, Printed list of facial expressions	Paper Format A4, Pencil Crayons 12 colors, a printed image of a person	Paper Format A4, Pencil Crayons 12 colors,	Paper Format A4, a printed list in two columns: hospital routine interventions v.s. coping strategies	Paper format A4, pencil Crayons 12 colors	Paper Format A4, Pencil crayons 12 colors	Paper Format A4, Pencil crayons 12 colors
Directive	I would like you to name this facial expressions, then for each emotion you can chose one of 12 colors that you thing fits the best with that emotion. If you like, you can put more than just one color.	Draw the portrait of yourself. After filling with the details, for each part of the body you can put different colors choosing one of 12 colors on the table.	Draw on the paper your perception, imagination, or even invention of pain. That can be an object, something found in the nature, in the house, school, or hospital, or a person with some distinct features	Link together the two columns with the hospital routines and what attitude or behavior characterizes that experience. Fill in with some other hospital routines and new strategies to deal with them.	Draw a pyramid with various scales (depending on how much you want to put) and fill all the scales with one activity, or thing you like very much to do but most of the time you can’t as you have pain, or have to be at the hospital.	Draw a person and an apple tree. At the end of the drawing from the pyramid of the other session, nominate each of the apples with the activities mentioned and written in the pyramid	Drawing a person picking the apple from the tree. Rank the apples (activities) based on their importance and find some strategies to catch the apple.
Purpose	To recognize facial expressions related to the emotions and identify the moment that cause them these expressions. Also identify your own color scale preference based on the emotions	Identify parts of the body and rank the level of pain experienced during the day by locating it with different colors and spreading the color to the area of pain	Increasing the awareness of pain and identifying it as an exterior object or person that we can control or monitor	Identify coping strategies while dealing with pain and hospital interventions and generating new experiences versus new coping strategies.	Feel free to express the frustration of everyday activities forbidden to attend as the result of pain and chronic disease, as well highlighting their importance on a scale.	Presenting the test by identifying the apples as the actives and positioning them on the tree (symbolizing the society) and presenting the person approaching or part of the society.	Encouraging the person to approach at the tree and generate coping strategies to achieve the activities wanted to have.

2.11. Case studies description

2.11.1. Participants in the experimental group

The 12 participants in the study are divided in two groups of 6 (3 boys and 3 girls for each group), the experimental group and the comparative group. The children on the experimental group were selected from the Pediatric Department of the Hospital Santa Maria, Lisbon, Portugal. The nurses and the pediatrician of the Pediatric Department with the permission of the Unit Director provided the information about their health conditions and diagnosis. During the art intervention sessions, children exchanged information regarding their family situation. Descriptive information for each case is as follows:

1- Patricia

Age: 7 years old

Diagnosis: Gaucher Syndrome.

Patricia was diagnosed with Gausher syndrome when she was 3 years old. Now she is 7 and the only one from the family diagnosed with this disease. Her older brother, is 12 years and never had any health complications. Both her parents work, but Maria has a special relation and affection for her father. She attends the elementary school. She prefers to come at the hospital with her father, as she defines it: "*It's safer with him.*"

The Gausher syndrome is an inherited disorder that affects many of the body's organs and tissues. The signs and symptoms of this condition vary widely among affected individuals. It occurs 1 in 50.000 to 100.000 people in general population. Type 1 is most common from the disorder, also called non-neuropathic Gausher disease because the brain and the spinal cord are usually not affected. Major signs and symptoms include enlargement of the liver and spleen, a low number of red blood cells (anemia), easy bruising cause by the decrease in blood platelets, lung disease, and bone abnormalities such as bone pain, fractures, and arthritis. (Beutler, 2006)

Patricia is 1m 30cm tall, using very good vocabulary for her age, with no physical abnormalities, and no cognitive development impairment. She feels at her ease in the presence of her father and craves for the attention of her

brother, wanting him to play with her. At first she is shy in the presence of a stranger, but if the activity involved is interesting, she is very active, even though she doesn't like to verbally interact. She wears eyeglasses, and her eye-hand coordination sometimes fails, which is the reason why she tends to hold the pencil tight and to approach too close to the paper. She gets tired very easily after 15 minutes of work, but resists without distraction. Her strong will to finish the task causes pain in her eyes, and then the blink for a long time till the blur goes away.

2. Alex

   Age: 12 years old

   Diagnosis: Sickle Cell Disorder

   Alex is diagnosed with Sickle Cell Disorder. The disease is part of a group of disorders that affect hemoglobin, the molecule in red blood cells that delivers oxygen to cells throughout the body. Usually begins in childhood. Characteristics of the disorder include a low number of red blood cells (anemia), repeated infections, and periodic episodes of pain. Painful episodes occur when sickled red blood cells get stuck in small blood vessels. It affects millions of people. It is more common among people with ancestors from Africa, Mediterranean countries such as Greece, Turkey, and Italy (Ashley-Koch, Yang, & Olney, 2000).

   Alex is an only child, with African origins. He is 12 years old, coming from a divorced family. His mother works during the day and sometimes has night shifts. She drops him at the hospital and Alex waits the entire day alone till she comes back to pick him up. He is very silent and stays in a corner of the room without approaching or playing with other children. The educators trick his attention with games or activities, but Alex prefers to stay alone. However, Alex craves for the attention of only one person. If a third person approaches he immediately goes to the corner of the room to listen to his favorite music. He comes at the hospital once per 20 days to have blood transfusion. His left arm, because of the vignettes, is numb, disguising his pretentious that he "*just wants to be alone*". Once asking Alex to draw, he enters into another world and everything around vanishes. He goes to the elementary school, but doesn't speak lot about it. His best friend, who was also his neighbor, left the town a few

months ago, so David has been feeling alone lately, especially because his house is located in the city periphery. The chronic disease was diagnosed by his third birthday. His mother, only twice stayed longer at the hospital during the research, mentioninng that he has never pain, but just craves attention.

3. Ricardo

   Age: 14 years old

   Diagnosis: Sideroblastic Anemia

   Ricardo was diagnosed with Sideroblastic Anemia when he was a few months old. His mother doesn't remember very well, as that period was very difficult for her family. Sideroblastic Anemia is a form of anemia in which the bone marrow produces ringed sideroblasts rather than healthy red blood cells (erythrocytes). It may be cause either by a genetic disorder or indirectly as part of myelodysplastic syndrome, which can evolve into hematological malignances. The anemia is very severe that requires continued blood transfusion (May et. al., 1982).

   Ricardo is now 14 years old and he confesses that the disease makes people treat him differently than before. He has the bone deformity and doesn't pose his feet entirely on the floor while walking. His hands resemble to a sponge. When holding his hand you feel no muscle or strength to shake, although he tries to grasp the pencil strongly. Ricardo doesn't have any cognitive impairment, although when he has to write, his hands sometimes tremble and his "*home works don't look so pretty as his classmates*" he adds.

   Ricardo worships football and his father takes him to the stadium every time a match of his favorite team plays. For his 13th birthday his father surprised him by taking him to meet his favorite football team. That day "*he is always going to remember*". He has an older brother, and since when they were little, he used to take care of Ricardo and now they are very close to each other. Both of Ricardo's parents work, but he feels very close to his father as they have many things in common - one and the most important of them is football. Coming from a family with lots of cousins and relatives, Ricardo never felt alone or excluded. He cherishes many beautiful memories from his childhood. However, the pain, hospital treatment, as well as two very protective parents, didn't permit him to follow the stages while growing up.

Ricardo wears eyeglasses, as his sight is getting more difficult with the passing of time, but he is willing that after computing 18 years he can have eye laser surgery. Talking to Ricardo is very easy. He is open, social, and smiling most of the time. He approaches easily to a stranger, also coming with the confidence of the age, but when alone with him, everything is the same, a very confident and calm boy. Drawing is a little bit difficult, as his hands get tired very easily. Through exercises, that he is willing to follow without any contest, he manages to accomplish the task.

4. Luis

   Age: 12 years old

   Diagnosis: Gaucher syndrome

   Luis is 12 years old, and diagnosed with Gaucher syndrome. He comes from a complicated family situation. He lives with his mother and grandmother. His grandmother, likes to come at the hospital with Luis.

   Luis was diagnosed when he was 2 years old. Despite the initial difficulties he now has a normal life, goes to school and has many friends. He doesn't like to talk very much and prefers to be silent and observe around. When asked to participate in an activity he plays the role of a lazy boy to be left alone. His grandmother and mother, when waiting at the hospital with Luis, barely talk to each other or even Luis. Instead, they look at their own agenda, or using the cellphones. He doesn't have any physical abnormalities, nor cognitive impairment, but sometimes stares at a specific point and focuses for several minutes, till getting out of the daydreaming.

5. Vanessa

   Age: 16 years old

   Diagnosis: Beta Thalassemia

   Vanessa is 16 years old. She is diagnosed with Beta Thalassemia when she was 1 years old. Being diagnosed with a chronic disease, is the only life she knows, although the gravity of her health situation is very low. Beta-Thalassemia is part of a group of inherited blood disorders. They are caused by reduced or absent synthesis of the beta chains of hemoglobin that results in variable outcomes ranging from severe anemia, to clinically asymptomatic individuals. Global annual incidence is estimated 1 in 100.000 (Rund &

Rachmilewitz, 2005).

Vanessa has e very protective mother, staying by her side all the time. Being a teenager she tries to avoid this chase. As they are part of the minority groups in Lisbon, Egyptians, Vanessa doesn't want to follow the same fate as many of her cousins or relatives, getting married at an early age. Recently she joined a religious doctrine, her family followed her too, mainly because the church helped her father find a job and they are monthly helping the family with food supplement. Vanessa rarely talks about her father, her mother is always present, difficult to miss the topic about her. The only person she talks the most is her cousin, three years older, recently married with a new born baby, that offers her interesting subjects and clothes for Vanessa to try when going at her place.

Vanessa doesn't have good results at school but she already discovered what she wants to do. The church is helping her attend a training for "nail esthetics" and she is excited to start it as soon as possible. This will give her "*independency and some time away from her mother's eye*".

Eleonor

Age: 9 years old

Diagnosis: Thalasemia

Eleonor is 9 years old diagnosed with Thalassemia. A pale tall girl, always dressed beautifully, and cleaned, pays too much attention not to mark her clothes or hands with colors. Thalassemia can cause complications, including iron overload, bone deformation, and cardiovascular illness (Rund, Rachmilewitz, 2005). Eleonor is a shy girl, needing the presence of her parents. Her mother, pregnant waiting for her little brother stays all the time waiting at the hospital, trying to make Eleonor talk and interact with the other children, but she never feels enough confident to leave the mothers clothes. Her father has more patients, saying that she needs her time to trust others and be active but the educators, despite the long time of knowing her, have never seen Eleonor play with other kids or be without the presence of her parents.

She is an only child at the moment, but soon she will have a younger brother. Her father works during the day and in the afternoon runs at the hospital to see how Eleonor is doing. Her eyes shine when she sees her father, and run to hug

him. She was diagnosed when she was 3 years old and since then, her mother says that she has had all the attention for herself, not only the parental one but from all the relatives as she was the first born. Talking to Eleonor takes a lot of time, and maybe even an hours for a short conversation as she smiles but never articulates words. When trying to talk she covers her mouth with the hands hardening the chances to be understood. Her mothers expresses that even at home she is very shy and rarely plays with her toys, unless someone she trusts takes her to play.

2.11.2. Participants in the reference comparative group

Participants in the comparative group were selected in the Consulta de Desenvolvimento in the Hospital Santa Maria, Lisbon, Portugal. The main educator of the center provided the information about each child health condition and diagnosis.

1. Bernardo

   Age: 18 years old

   Diagnosis: Renal Insufficiency

   Bernardo is 18 years old diagnosed with Renal Insufficiency. Chronic kidney disease is also called chronic renal failure or chronic renal insufficiency. Chronic kidney disease is cause by damage to the kidney such as high blood pressure over the years, high blood sugar over many years especially from the uncontrolled type 1 and 2 of diabetes (National Institutes of health, 2012). He has a younger sister, but his relations with her are not very strong as in his age he prefers to be alone and keep his things away from his sister.

2. Mariana

   Age: 15 years old

   Diagnosis: Thalassemia

   Mariana is 15 years old diagnosed with Thalassemia. Accompanied by her mother, a very smiling girl, visits the Consulta de Desenvolvimento for regular checkups depending on the schedule prepared by her pediatrician. Has an older brother. Both her parents work and most of the time, especially during the summer she has to take care of the house. She takes the role of her mother

and helps her little brother to feed dress up.

3. Pedro

   Age: 13 years old

   Diagnosis: Thalassemia

   Pedro is 13 years old diagnosed with Thalassemia. No physical abnormality, or cognitive impairment diagnosed. Always accompanied by his father as a very good support and attention. Pedro's mother is working during the day and she can't join him at the hospital. Pedro has a strong connection with his father. He has a younger brother. They don't like to hang out a lot with each other, especially because Pedro is older and liked play videogames, whereas his brother is not allowed to stay long in front of the computer.

4. Liliana

   Age: 12 years old

   Diagnosis: Gaucher syndrome

   Liliana is 12 years old diagnosed with Gausher Syndrome. She is very shy and needs the attention or presence of one of her parents to assist in every new approach. She likes colors and as many colors presented to her the best, so she can play and amuse herself, as long as someone else approaches and she hides behind her mother. Liliana has an older sister. Her parents are very supportive, although, never giving the chance for Liliana to gain confidence and handle her situation alone.

5. Cristiano

   Age: 10 years old

   Diagnosis: Beta-Thalassemia

   Cristiano is 10 years old wearing the shirt of the football player Ronaldo all the time, and even cutting his hair to look like him. He is diagnosed with Beta-Thalassemia. No physical abnormalities, although his hands sometimes are very week and hardens the chances to hold heavy things. He tries and in case of emergency, his mother is always present helping him, and playing with him, till phone call from her work arrives and she has to live. Cristiano has to be in the center alone till he finishes with the treatment. Some educators are very affective to him and after so many tears he has gained confidence in them. Cristiano has a younger sister.

6. Carla

Age: 8 years old

Diagnosis: Epilepsy

Carla is 8 years old diagnosed with Epilepsy. Last few months she has been experiencing more than usual seizures, which is the reason why she comes to the hospital often. A new diagnose or medical treatment is needed and she isn't willing to take it seriously as she doesn't want to come at the hospital. Her mother is very worried and willing to lose her job is necessary to have her daughter feel better. Carla has an older brother, very attached to him. She follows him everywhere, although sometimes he refuses her company because she is "*childish*", referring to her definitions.

CHAPTER 3

RESULTS

3. RESULTS

3.1. Results from the Adolescents Pediatric Pain Tool (APPT) for both groups before the art intervention

The pediatric questionnaire was the first administered instrument. The test has three subscales, as shown in Table 5. The test utilizes a ruler (1-10 cm) to measure the map of the pain children self-assesses in the test (refer to Appendix F). The head and the feet are two most frequent locations of pain. Four out of six children in the experimental group have selected head; mapping an area of max. 2 cm and min. 1 cm (refer to the instrument description for the scoring process).

Table 5. Description data statistics from the APPT for the experimental groups before the art intervention (N=6)

	Pain Location	**Pain Intensity**	**Sensory**	**Affective**	**Evaluative**	**Temporal**	**Total**
Patricia	Head- 2 cm Hand- 1cm Feet – 1 cm Back – 3 cm Neck – 0.5 cm	High level of pain	0 %	0.19 %	0.25%	0.45%	0.13%
Alex	Head – 1 cm Shoulder – 3 cm Left leg – 7 cm	High level of pain	0.22 %	0.27%	0.5%	0.09%	0.24%
Ricardo	Head – 2 cm Legs – 7 cm (each) Arm – 3 cm (each)	High level of pain	0.22%	0.09%	0.38%	0.36%	0.24%
Luis	Chest – 3 cm Head – 1 cm Shoulder – 2 cm Knee – 0.5% Pulse – 1 cm	Medium level of pain	0.22%	0.27%	0.5%	0.9%	0.37%
Vanessa	Back – 2 cm Pulse – 1 cm Menstruation pain	Medium level of pain	0.05%	0%	0.12%	0.18%	0.07%
Eleonor	Head - 1 cm Left hand – 1 cm Chest – 2 cm Feet – 1 cm (each)	Medium level of pain	0.49%	0.45%	0.37%	0.45%	0.46%

Three children declared to have a high level of pain while the other three had medium level pain. The pain is divided into three perceptive scales: Sensory or differently connected with cognitive perceptions, affective, evaluative, and temporal. There is a very small difference in pain assessment between the control group and the experimental group (Table 6), although the shoulder

seems to be the most common area of pain, and with a sliced difference on the level of pain. Two of them declared high level of pain and four out of six reported medium level of pain (Table 6). The results also show that the higher the level of pain, the more prompt it will be evaluated.

However, in the case of Ricardo, family members were very conscious of his pain, mainly because of his bone deformation. Ricardo ranked his pain as high level, also, while describing the pain distribution across the body it was higher compared to that of other children. Nevertheless, based on his pain perceptive ranking, the words he selected were "annoyed," "pulping," "like a shock," "numb," "uncontrollable," "comes out of a sudden" resulting in him mainly having a temporal pain. In contrast, Patricia classified a high level of pain but using "horrible," "pressure," "hot," "miserable," "sometimes," "comes out of a sudden" to refer to pain. Her ranking was also a temporal pain. In the cases of Bernardo and Christiano, from the comparative group, both selected a high level of pain and described it as "horrible," "suffocating," "terrifying," "Once in a while" for Christiano, and "scratching," "bad," "aching" for Bernardo. Regarding the case of Mariana with a medium level of pain, she has a more "evaluative" type of pain, which refers better to their high sensitivity to perceive the pain or better evaluate the pain by introducing references such as "annoyed," "uncomfortable," "terrible," "uncontrollable," etc.

Another participant having temporal pain was Vanessa, with medium level of pain using descriptive words such as "annoyed', "sensitive," "numb," "steady." A temporal level of pain is a sudden experience of pain, though not continuous, its intensity varies depending on the chronic disease. Such is the experience for Christiano, Liliana, and Carla with a temporal level of pain. In the case of Alex, the level of pain is high as his blood cells get stuck in small vessels thereby, depriving his body from getting the necessary oxygen. This is why he refers to pain as "annoying", "killing", "numb", "uncontrollable", "pressure", and "forever". The descriptive pain scale is "affective," reasonably, for continuously affecting his life and always being present.

Different from Alex, Eleonor has a medium level of pain and mainly described as “Sensory” the reason why she chose words such as “unhappy”, “terrible”,

"pinching", "hot", and "pressure". Although, Eleonor is very shy, her pain description surprised even her parents, as she never complains. In this context, she has a positive family model, masking her perceptions to the nurses or pediatricians, but as an introvert, the family despite the positive model needs other means of communication.

In comparison with the other group (Table 6) the higher the level of pain the higher the sensory descriptive pain. The other scales have almost the same distribution of values as in the first group. Again, in the case of Bernardo, he shows a high level of pain and also a high pain perception on the three descriptive subscales.

Table 6. Descriptive data statistics from the APPT for the comparative group at the baseline (N=6)

	Pain Location	**Pain Intensity**	**Sensory**	**Affective**	**Evaluative**	**Temporal**	**Total**
Bernardo	Shoulder – 3 cm Head – 2 cm Feet – 1 cm (each)	High level of pain	0.65%	0.64%	0.63%	0.45%	0.61%
Mariana	Left arm – 3 cm Feet – 1 cm (each) Arm – 1 cm	Medium level of pain	0.29%	0.27%	0.36%	0.09%	0.24%
Pedro	Head – 1 cm Shoulder – 2 cm Stomach – 2 cm	Medium level of pain	0.19%%	0.09%	0.12%	0.36%	0.19%
Liliana	Chest - 2 cm Right leg – 2 cm Right shoulder – 1 cm Neck – 1 cm Eyes – 0.5 cm	Medium level of pain	0.29%	0 %	0.25%	0.45%	0.27%
Cristiano	Neck – 1 cm Stomach – 2 cm Left leg – 5 cm Shoulder – 3 cm	High level of pain	0.38%	0.27%	0.25%	0.36%	0.34%
Carla	Head – 2 cm Eyes – 1 cm Neck – 1 cm Arms – 3 cm (each) Right leg – 2 cm	Medium level of pain	0.19%	0.09%	0.25%	0.27%	0.19%

Despite the small differences in the level of pain and perception, the distribution of values is almost the same, which makes possible, a fair comparison between the two groups. The words used in the APPT test were very important during the art intervention, as it evaluates the self-awareness of pain and emotion perceptions. In Table 7 is described the distribution of descriptive pain word frequency among the 12 children, as both groups had the same composition. The more frequent words used to describe pain were "annoying,"

"uncomfortable," "steady," "comes on all of a sudden," "awful," "constant," and "continues." The group of temporal descriptive subscale has a higher frequency of usage compared to the other subscales.

Table 7. Frequency of the descriptive pain word selection subscale for both groups at the baseline (N=12)

	Sensory	Affective	Evaluative	Temporal
Aching	0,08			
Hurting	0,02			
Like an ache	0,11			
Like a hurt	0,08			
Sore	0,21			
Beating	0,11			
Hitting	0			
Pounding	0,02			
Punching	0,05			
Throbbing	0			
Biting	0,21			
Cutting	0,11			
Like a pain	0			
Like a sharp knife	0,02			
Pin like	0			
Sharp	0.02			
Stabbing	0,21			
Blistering	0			
Burning	0,11			
Hot	0.21			
Cramping	0			
Crushing	0.02			
Like a pinch	0			
Pinching	0.08			
Pressure	0.21			
Itching	0.11			
Like a scratch	0.02			
Like a sting	0.08			
Scratching	0.02			
Stinging	0,13			
Shocking	0.11			
Shooting	0.11			
Splitting	0.08			
Numb	0,19			
Stiff	0.08			
Swollen	0.08			
Light	0.08			
Awful	-	0,54		
Deadly	-	0,18		
Dying	-	0,09		
Killing	-	0,27		
Crying	-	0,09		
Frightening	-	0,18		
Screaming	-	0,27		
Terrifying	-	0,18		
Dizzy	-	0,09		
Sickening	-	0,27		
Suffocating	-	0,27		
Annoying	-	-	0,87	

	Sensory	Affective	Evaluative	Temporal
Bad	-	-	0,12	
Horrible	-	-	0,62	
Miserable	-	-	0,25	
Terrible	-	-	0,37	
Uncomfortable	-	-	0,62	
Never goes away	-	-	0,37	
Uncontrollable	-	-	0,5	
Always	-	-	-	0,45
Comes and goes	-	-	-	0,54
Comes on all of a Sudden	-	-	-	0,54
Constant	-	-	-	0,27
Continues	-	-	-	0,45
Forever	-	-	-	0,45
Off and on	-	-	-	0,36
Once in a while	-	-	-	0,45
Sneaks up	-	-	-	0,36
Sometimes	-	-	-	0,27
Steady	-		-	0,63

3.2. Results from the Pain Coping Questionnaire (PCQ) for both groups before the art intervention

The Pain Coping Questionnaire measures coping strategies related to pain. Based on Table 8, the results show that in both groups the two most evaluated scales are the "Approach" and "Distraction." The "distraction" scale however, has a higher value. In respect to the subscales, children have selected "Information seeking," "Behavioral distraction" and "Cognitive distraction" more often, leaving such a high difference with the "Externalization" subscale. The distribution is almost the same for the other group, although there is a slice difference in the subscale of "Approach." Children have highly selected "Seeking social support" in comparison with the first group selecting "Information seeking."

Despite the higher result of the "Approach" and "Distraction" based on the Likert scale measuring the frequency of behaviors' performance, there is a difference among the subscales (Table 10). Such findings show that children are more interested in finding a solution to their situation but indulge in more distractive behaviors or in the case of the comparative group (Table 11) "externalizing and internalizing."

Table 8. Mean and standard deviation for the coping scales/subscales from the PCQ for both groups at the baseline

Children part of art intervention (N=6)			**Children not part of the art intervention (N=6)**	
Coping Scales	**Mean**	**Standard Deviation**	**Mean**	**Standard Deviation**
Approach	2.8	1.12	2.3	0.96
Distraction	3.8	1.27	3	1.37
Emotion-focused avoidance Subscales	1.88	0.96	1.7	1.3
Information seeking	2.8	0.98	2.2	0.75
Problem Solving	2.5	1.37	2.3	1.2
Seeking social support	3.3	1.03	2.8	1.17
Positive self-statement	2.2	0.98	2	0.62
Behavioral Distraction	4.5	0.83	2.7	1.21
Cognitive distraction	3,2	0.75	4.3	1.03
Externalizing	0.8	1.74	0.7	0.51
Internalizing/Catastrophizing	1.7	1.03	2.7	1.03

As previously mentioned in the APPT the results for each of the children in both groups in Table 9 present individual results for both groups.

Table 9. Descriptive results for each of the 12 children individually from the PCQ questionnaire at the baseline

Experimental group (N=6)	Approach (%)	Distraction (%)	Emotion-focused (%)
Vanessa	0.57	0.66	0.1
Alex	0.36	0.73	0.6
Patricia	0.74	0.8	0
Eleonor	0.38	0.47	0.8
Ricardo	0.84	0.87	0.5
Luis	0.68	0.86	0.3
Comparative Group (N=6)	-	-	-
Bernardo	0.42	0.73	0.4
Mariana	0.63	0.53	0.1
Pedro	0.57	0.66	0.6
Liliana	0.42	0.72	0.3
Cristiano	0.52	0.46	0.3
Carla	0.42	0.53	0.5

Considering the positive family model, Ricardo has a very caring and protective family, always present, calling him at all times to know that he is fine, consequently, and his coping scales results are "Approach" (84%) and "Distractive" (87%). Although the distractive behaviors contain the majority of his answers, which include "Ask questions about the problem," "Think about what needs to be done to make things better," and "Tell it is not that bad." But most of the questions and the higher frequency of performing them are included in the "Distraction" scale, mainly "Behavioral Distractions" such as "Do something fun", "Do something I enjoy" and the "Cognitive Distractions"

answers are: “Try to forget it”, and “Don’t think about it”. As a result, from the general result of the group, when the pain perception is "Temporal" there are higher chances that the children will seek for active coping strategies such as "Problem-Solving" or "Seek Social Support" and lower chances for "externalizing" and "internalizing." The lower the pain level, the higher the chances to ask for support, self-efficacy, etc. Such are the cases of Cristiano and Mariana from the comparative group, having higher approach scale scores compared to the distraction scale.

The same conditions are captured in Patricia's case. Her model family and the relationship with her father help her to develop a variety of alternatives to cope with the situation. However, same as Ricardo, her coping scales results are "Approach" (0.57%) and "Distraction" (0.66%). Her higher-ranking subscales of the “Approach” varies among "Seeking Social Support" such as "Tell a family member how I feel," "Tell someone how I feel", and in the "Distractive" include the majority of her selected replies and the higher frequency of performing such as "Put it out of my mind," "Think about it," "Tell myself it's not so bad," and "Do something to take my mind off it." The same conclusions are arrived at for Patricia’s, as the pain is ranked Temporal, the chances to ask for help and seek support is higher, compared to the others.

Meanwhile, in the case of Eleonor, who is very shy and socially introvert, and Alex who is socially withdrawn, their results stand as follows. Eleonor’s perception of pain is mainly sensory, but that doesn’t make any difference or the higher/lower importance from the “Affective” perception of pain in the case of Alex. Eleonor reflects a high difference between the “Approach" and "Distractive" scales, corresponding (36%) with (73%). Her main answers and high frequency coping strategies were "Behavioral Distraction" such as "Go to play", "Do something to take my mind off", "Cognitive Distraction” such as "Forget the whole thing", "Ignore the situation", and "Internalizing" such as "Keep thinking how much it hurts", and "Think the pain will never stop".

Alex, for instance, has mainly “Distractive” strategies (54%). His replies reflect the conflicting family situation and social complex. Alex prefers to be alone and not to talk to anybody, as reported by the hospital nurses. Most frequent coping

strategies he selected are “Cognitive Distraction” such as "Forget the whole thing," "Put it out of my mind," "Think about it" and “Internalizing” such as "Think that nothing helps" and "Keep thinking how much it hurts."

Table 10. Frequency of each performed behaviors grouped in coping subscales from the PCQ for children in the experimental group (N=6)

Items	Factors							
	Information Seeking	Problem Solving	Seeking social support	Positive self-statement	Behavioral distraction	Cognitive distraction	Externalizing	Internalizing /Catastrophizing
Ask question about the problem	2.33							
Ask a nurse or doctor questions	1.83							
Find out more information	2.17							
Learn more about how my body works	2.67							
Focus on the problem and see how I can solve it	-	2.83						
Think about what needs to be done to make things better	-	2.33						
Think of different ways to deal with the problem	-	2						
Figure out what I can do about it	-	2.67						
Try different ways to solve the problem until I find one that works	-	1.67						
Talk to a friend about how I feel	-	-	2					
Talk to someone about how I am feeling	-	-	2.83					
Tell someone how I feel	-	-	2.83					
Talk to a family member about how I feel	-	-	2.67					
Let my feelings out to a friend	-	-	1.67					
Tell myself, don’t worry everything will be OK	-	-	-	2.17				
Say to myself, be strong	-	-	-	1.5				
Tell myself it’s not so bad	-	-	-	2.33				
Tell myself I can handle anything that happens	-	-	-	2.83				
Say to myself things will be OK	-	-	-	2.5				
Go and play	-	-	-	-	3.5			
Do something fun	-	-	-	-	3.67			
Do something I enjoy	-	-	-	-	4.17			
Do something active	-	-	-	-	3.83			
Do something to take my mind off it	-	-	-	-	3.67			
Forget the whole thing	-	-	-	-	-	3.83		
Ignore the situation	-	-	-	-	-	3.8		
Try to forget it	-	-	-	-	-	3.83		
Put it out of my mind	-	-	-	-	-	2.5		
Don’t thing about it	-	-	-	-	-	3.33		
Say mean things to people	-	-	-	-	-	-	1.83	
Argue or fight	-	-	-	-	-	-	1.17	
Yell to let of steam	-	-	-	-	-	-	1.83	
Get mad and throw or hit something	-	-	-	-	-	-	1.5	
Curse out loud		-	-	-	-	-	1.33	
Worry that I will always be in pain	-	-	-	-	-	-		1.3
Keep thinking about how much it hurts	-	-	-	-	-	-		2
Think that nothing helps	-	-	-	-	-	-		2.33
Think that the pain will never stop	-	-	-	-	-	-		2.17
Worry too much about it	-	-	-	-	-	-		1.17

Luis and Vanessa have a lower level of pain, and that is also shown in the results from the descriptive pain words. Nevertheless, there is a slight difference

between Luis, who is younger, as despite the family situation he still has two women taking care of him, and giving him a family. Once more, in these cases the difference between "Approach" and "Distractive" is not big, respectively (0.74%) and (0.82%).

Table 11. Frequency of each of performed behaviors grouped in coping subscales from the PCQ for children in comparative group at the baseline (N=6)

Items	Factors							
	Information Seeking	Problem Solving	Seeking social support	Positive self-statement	Behavioral distraction	Cognitive distraction	Externalizing	Internalizing /Catastrophizing
Ask question about the problem	1.83							
Ask a nurse or doctor questions	2							
Find out more information	1.33							
Learn more about how my body works	1.33							
Focus on the problem and see how I can solve it	-	1.67						
Think about what needs to be done to make things better	-	1.33						
Think of different ways to deal with the problem	-	1.5						
Figure out what I can do about it	-	1.67						
Try different ways to solve the problem until I find one that works	-	1.65						
Talk to a friend about how I feel	-	-	1.83					
Talk to someone about how I am feeling	-	-	1.67					
Tell someone how I feel	-	-	1.33					
Talk to a family member about how I feel	-	-	1.33					
Let my feelings out to a friend	-	-	1.16					
Tell myself, don't worry everything will be OK	-	-	-	1.5				
Say to myself, be strong	-	-	-	1.17				
Tell myself it's not so bad	-	-	-	1.5				
Tell myself I can handle anything that happens	-	-	-	1.5				
Say to myself things will be OK	-	-	-	1.67				
Go and play	-	-	-	-	3.17			
Do something fun	-	-	-	-	2.67			
Do something I enjoy	-	-	-	-	2			
Do something active	-	-	-	-	2.17			
Do something to take my mind off it	-	-	-	-	1.67			
Forget the whole thing	-	-	-	-	-	2.5		
Ignore the situation	-	-	-	-	-	1.5		
Try to forget it	-	-	-	-	-	3.17		
Put it out of my mind	-	-	-	-	-	3		
Don't thing about it	-	-	-	-	-	2.33		
Say mean things to people	-	-	-	-	-	-	2.5	
Argue or fight	-	-	-	-	-	-	1.3	
Yell to let of steam	-	-	-	-	-	-	1.35	
Get mad and throw or hit something-	-	-	-	-	-	-	1	
Curse out loud		-	-	-	-	-	1	
Worry that I will always be in pain	-	-	-	-	-	-		2.7
Keep thinking about how much it hurts	-	-	-	-	-	-		2.33
Think that nothing helps	-	-	-	-	-	-		2.17
Think that the pain will never stop	-	-	-	-	-	-		1.83
Worry too much about it	-	-	-	-	-	-		1.5

The coping strategies selected from the “Approach” scale are "Problem Solving" subscale such as "Think of different ways to deal with the problem", "Figure out what I can do about it", and "Seeking social support" subscale such as, "Talk to a friend about how I feel", and "Tell a friend how I feel". Vanessa, instead, especially regarding her age as a teenager and her overprotective mother, and the pain classification, selects "Internalization" subscale such as "Think that nothing helps," and "Worry too much about it."

The most frequent answers from the "Information Seeking" in the experimental group are: "Ask a question about the problem"; "Learn more about how my body works." In the highest score scale “Distraction", the most frequent selected answers in the "Cognitive distraction" are: "Forget the whole thing"; "Try to forget"; "Ignore the situation", "Put it out of my head", while the "Behavioral Distraction" are: "Do something active"; and "Do something I enjoy" (Table 10).

Regarding both groups, despite the low numerical answers for the "Internalizing" subscale, the frequency of performing these coping strategies is higher, with almost the same frequency as the "Information Seeking" or "Problem-Solving". The most frequent replies on this subscale are "Think that nothing helps," and "Think that the pain will never stop."

Table 12. Descriptive correlation of coping scales/subscales and age in both groups at the baseline (N=6)

Coping scales	Age Experimental group	Age comparative group
Approach	0.41	0.16
Distraction	0.48	0.56
Emotion-focused	0.37	0.32
Coping Subscales		
Information seeking	0.58	0.39
Problem Solving	0.53	0.03
Seeking social support	-0.25	-0.16
Positive self-statement	0.02	0.32
Behavioral Distraction	0.66	0.66
Cognitive distraction	0.59	0.03
Externalizing	0.13	0.04
Internalizing/Catastrophizing	0.49	0.47

In table 12, are distributed the correlation values between each scale/subscale and the children's age. As described in the table, children from both groups have a positive correlation between age and distraction coping scale. Although,

regarding the first scale "Approach" there is a big difference between the two groups, with a positive correlation. In the experimental group, the correlation value for the approach is (0.41) while in the comparative group it is (0.16). An interesting result is the negative correlation between the age and the “Seeking Social Support” coping subscale, indicating the age of the child going contrary to their need to ask for support. Such interesting factors are the same value correlating positively the age with the “Behavioral Distraction” subscale.

Continuously, in Table 13 are represented the mean and the standard deviation for each of the scales/subscales and gender for both groups. In both groups children, despite their ages, have selected same coping strategies they use more often while dealing with the disease. The “Distraction” scale has a higher value compared to the others with a slight difference between the two genders, valid for both groups. However, the “Behavioral Distraction” subscale is higher for the experimental group and the Cognitive Distraction is also higher for the comparative group, compliment of the results from Table 8.

For both groups, there is a division of 3 girls and 3 boys. From table 13, the results describe a similar selection of the coping strategies. A very important task is to find the correlation between pain perception and coping strategies. The values described in Table 14 describe the correlation of the pain subscales results from the APPT and the 8 subscales of coping strategies from the PCQ. The "Approach" subscales such as "Information seeking" and “Problem Solving” have a negative correlation with the pain perception, more specifically the "Affective" pain subscale and the "Temporal" pain subscale. Differently, the higher the level of pain the lower is the urge to search for information. Although, the first group shows that the "Problem Solving," "Seeking Social Support" and "Positive Self-Statement" have a positive correlation with the "Temporal" pain subscale. It is more plausible when the pain is, the more children seek for active coping strategies and vice versa, when pain is more constant, the more children ask for internalizing approaches or behavioral distraction. A very interesting perspective arises between two distinct subscales such as "Distraction" and "Sensory" perception of pain. There is a negative correlation between the sensory pain and the behavioral distraction, or differently described as the higher the awareness and perception of pain, the higher the need for

distraction. Otherwise, what happens with the “Cognitive distraction” and the “Sensory” perception of pain reveals that when having higher cognitive awareness of the pain perception, the lesser you search for cognitive justification.

Table 13. Mean and Standard Deviation for each of the scales and subscales of the coping related to pain based upon the gender for each group at the baseline

Children part of art intervention (N=6) *Male N=3* *Female N=3*			**Children not part of the art intervention (N=6)** *Male N=3* *Female N=3*	
Coping Scales	**Mean**	**Standard Deviation**	**Mean**	**Standard Deviation**
Approach				
Male	2.9	4.04	2.4	1.52
Female	2.5	2.64	2.3	2.31
Distraction				
Male	3.5	1.52	3.1	2.08
Female	3.1	0.57	3	1.73
Emotion-focused avoidance				
Male	1	1.73	1.8	0.57
Female	1.5	1.73	1.5	2
Subscales				
Information seeking				
Male	3	1	2	1
Female	2.7	1.15	2.3	0.57
Problem Solving				
Male	3	1.73	2	1
Female	2	1	2.6	1.52
Seeking social support				
Male	3.3	1.52	3.6	0.57
Female	3.3	0.57	2	1
Positive self-statement				
Male	2.3	1.15	2	0
Female	2	1	2.3	0.58
Behavioral Distraction				
Male	4.6	0.57	3	1
Female	4.3	1.15	2.3	1.52
Cognitive distraction				
Male	3.3	0.57	4.3	1.15
Female	3	1	4.3	1.15
Externalizing				
Male	0.7	0.57	0.6	0.57
Female	1	1	0.6	0.57
Internalizing/Catastrophizing				
Male	1.3	1.15	3	0
Female	2	1	2.3	1.53

In the comparative group, it is almost the same distribution, with only a few changes among the pain perceptions subscales. There is a positive correlation between “Approach” coping strategies and the “Sensory” pain description subscale. Likewise, when there is a high value of negative correlation between

the "Distraction" scale and the "Sensory" subscale, it rotates the results encountered in the first group between “cognitive” and “behavioral” distraction. An interesting encounter is between “Emotional Focused Approach” and the “Temporal” descriptive pain subscale, inducing a negative correlation. The higher the temporal level of pain (lasting for a relatively short term) the lower the chances for externalizing and internalizing emotions.

Table 14. Correlation between the coping subscales PCQ and categories of pain APPT for both groups at the baseline (N=6)

Coping/Pain	Experimental group				Comparative group				
	Sensory	Affective	Evaluative	Temporal	Sensory	Affective	Evaluative	Temporal	P value
Information seeking	-0.28	-0.77	-0.37	-0.61	-0.35	-0.24	-0.39	-0.37	0.21
Problem Solving	-0.32	-0.57	-0.06	0.48	-0.22	-0.37	-0.59	0.62	0.82
Seeking social support	-0.21	0.03	0.05	0.92	0.09	0.29	0.01	0.57	0.93
Positive self-statement	-0.56	-0.51	-0.14	0.54	-0.11	-0.06	-0.38	0.70	1
Behavioral Distraction	0.53	0	-0.11	-0.49	0.54	0.31	0.48	0.47	0.01
Cognitive distraction	-0.64	-0.65	-0.18	0.21	-0.02	-0.05	0.35	-0.36	0.04
Externalizing	0.73	0.35	0.03	-0.46	-0.02	-0.05	0.35	-0.36	0.66
Internalizing/Catastrophizing	0.02	-.36	-0.55	-0.86	-0.04	0.12	0.31	-0.92	0.12

*Significance difference ($P < 0.05$)

3.3. Results from the KIDCOPE questionnaire for both groups before the art intervention

Lastly, the KidCope questionnaire measures the same scales as referred to in the PCQ, but divided differently, aiming to evaluate the coping strategies children diagnosed with a health condition use in their everyday life situation that they consider hurtful or of bad experience. This test, offers two different situations, one that is already provided from PCQ and the second one is adding two different subscales of coping that contemplate emotional description of coping strategy such as anger, anxiety, and sadness (Refer to Appendix E).

In Table 15, in both groups, children have selected “Distraction” subscale, “Social Withdrawal”, “Wishful Thinking”, “Internalized Emotions”, and “Resignation”. Children perceive that these behaviors help them more as opposed to using the other coping strategies such as “Problem-Solving”, “Social Support”, etc. Again, as presented in the results of the first questionnaire, the "Externalizing" coping strategy had a very low frequency and resulted to also having a very low level of effectiveness perceived.

In the case of Patricia, she selected "Social Withdrawal", "Wishful Thinking" and "Internalizing" subscales such as "I stayed by myself ", "I wished I could make things different", "I tried to calm myself down", and indicated that these strategies were very helpful although with a high level of sadness and anxiety. All of these criterions symbolize Patricia's everyday life. Two most extreme cases selecting "Wishful Thinking" are Bernardo and Pedro from the comparative group replying with high frequency "Wished the problem never happened," and "Wished things were different."

Table 15. Mean and Standard Deviation for both groups ranking the effectiveness scale at the baseline (min/max value)

	Experiment group			Comparative group		
Kidcope Subscales	Mean	Standard Deviation	Min/max	Mean	Standard Deviation	Min/max
Distraction	3.5	2.34	0/6	2.3	2.33	0/6
Social withdrawal	2.3	1.36	0/4	1.8	1.17	0/3
Wishful thinking	3	2.09	0/6	2.8	1.13	0/6
Self-criticism	0.2	0.41	0/1	1	1.09	0/2
Blame others	0.3	0.81	0/2	0.2	0.41	0/1
Problem solving	2.3	1.63	0/2	1.7	1.63	0/4
Internalized emotions	2.3	1.21	0/3	2.8	0.41	2/3
Externalized emotion	0.5	1.22	0/3	0.5	0.83	0/2
Cognitive restriction	1	1.26	0/3	0.6	0.81	0/2
Social Support	1.2	1.47	0/3	0.6	1.21	0/3
Resignation	2.4	1.21	0/3	2.3	0.51	2/3

With almost the same results but performing more distracting activities such as "I did something like TV or playing games," in the case of Luis, is referred to as low level of anxiety (Table 15). For Luis, pain is very low, and also distraction makes the anxiety coming from wishful thinking and social withdrawal less stimulating. Differently, from the other test, Ricardo performs "Distractive" behaviors and "Internalizing" emotions, and to his perceptions, they were very helpful although with a high level of anxiety. Distracting and keeping the emotions or thoughts inside doesn't get the problem to go away, it just represses to erupt at any time during the day, which raises the anxiety, for the moment of facing the problem. Such as Carla in the comparative group frequently does "Tried to forget," and "Tried to do something else like watch TV or play games."

The same conclusions are applicable to the cases of Vanessa and Eleonor. Despite their differences in pain level, they both choose distraction. Vanessa is

more focused on “Wishful thinking” and “Resignation" such as "I didn't do anything as the problem couldn't be fixed" to help her face difficulties, although, it increases the level of sadness and anxiety. A little different, Eleonor from the experimental group and Pedro from the comparative group, selected "Social withdrawal" as helping them face stressful situations. Once again, the coping strategies were affective for the moment but were followed by high level of anxiety. Subsequently, the higher level of pain such as the conditions of Eleonor are, correspond with social withdrawal and anxiety. Liliana and Carla selected “Resignation” scale frequently, followed by anxiety and sadness. Alex instead, different from the others, also has a higher level of anger brought on by three coping strategies such as “Distractive”, “Social withdrawal”, and “Wishful Thinking”.

The correlation between coping strategies’ effectiveness with the emotional scale among three emotional subscales of KidCope, sadness, anxiety, and anger, is evaluated in Table 16. The experimental group perceived that when facing a stressful situation it is more effective to perform “Social Withdrawal” and “Wishful Thinking”, although it results in high level of anger, anxiety, and sadness. A fair interpretation would be that children believe that social withdrawal and wishful thinking helps them to deal with the situation but on the other side causes a higher level of sadness, anxiety, and anger. Interestingly, there is a positive connection between “Social Support” and the three emotive subscales. In the comparative group, however, there is a more negative correlation, especially a profound difference between “Distraction” and “Anxiety”. The higher the level of distraction (limiting yourself to deal actively with the stressful situation); the lower the level of anxiety (blocking the process of thinking). The same happens with “Self-Criticism” and the three subscales, having a negative correlation. In conclusion, the higher the level of self-criticism, the lower the level of sadness, anxiety, and anger. Besides, there is an interesting positive correlation between “Cognitive Restriction” and anxiety and anger. Thus, the more you rationalize, the higher seems to be the level of anxiety as well as anger.

Table 16. Descriptive correlation between the coping subscales KidCope and the emotional reaction for both groups at the baseline (N=6)

Kidcope Subscales	Correlation variables 1 group			Correlation Variable 2 group		
	Sadness	Anxiety	Anger	Sadness	Anxiety	Anger
Distraction	-0.08	0	0.07	0	-0.62	-0.15
Social withdrawal	0.47	0.62	0.53	0.19	0.15	0.15
Wishful thinking	0.36	0.13	-0.17	0.11	0.08	-0.42
Self-criticism	-0.15	0	0.44	-0.41	-0.33	0.33
Blame others	0.31	0.34	0.45	0.54	0.89	0.44
Problem solving	0.51	0.34	-0.17	-0.13	0	0.89
Internalized emotions	0.21	0.12	-0.31	0.55	0	0.44
Externalized emotion	-0.15	0	-0.44	-0.26	0.03	0.21
Cognitive restriction	0.61	0.67	0.29	0.27	0.76	0.89
Social Support	0.48	0.57	0.12	-0.18	0.43	0.31
Resignation	-0.11	0.11	0.31	0.48	0.71	0.72

In table 17 are presented the mean (M) and standard deviation (SD) for each of the coping subscales from the KidCope questionnaire for both groups based on their gender differences. Interestingly, the same as from the PCQ, the results are very tight from each other. Boys in both groups perceive more “Distraction”, “Wishful Thinking”, “Internalizing,” and “Resignation” coping strategies. For the girls it is the same, with one small difference, performing less frequently these abovementioned coping mechanisms in comparison to boys.

Table 17. Mean and Standard Deviation for the coping subscales in the KidCope questionnaire and gender for both groups at the baseline (N=6)

Coping Strategies	Experimental Group				Comparative group			
	Mean		SD		Mean		SD	
	Male	Female	Male	Female	Male	Female	Male	Female
Distraction	5.3	1.6	1.15	1.52	3.3	1.3	2.31	2.31
Social withdrawal	1.6	3	1.52	1	2	1.6	1.73	0.57
Wishful thinking	2.6	3.3	1.15	3.05	4	1.7	1.73	2.08
Self-criticism	0	0.3	0	0.57	1.6	1.3	1.15	1.15
Blame others	0.6	0	1.15	0	0	0.3	0	0.57
Problem solving	2.3	2.3	0.57	2.51	1.3	2	1.53	2
Internalized emotions	3	1.6	0	1.52	3	2.7	0	0.57
Externalized emotion	1	0	1.73	0	1	0	1	0
Cognitive restriction	0.6	1.3	1.15	1.53	0.3	1	0.57	1
Social Support	1	1.3	1.73	1.52	0	1.3	0	1.53
Resignation	3	1.7	0	0.49	2	2.7	0	0.58

3.4. Description of art intervention seven sessions

Art intervention sessions started in May 2015 and continued during the summer time. The work at the hospital continued as regular despite health care providers vacations. Only one participant from the experimental group left for 15 days at a summer camp organized by the hospital Santa Maria staff. Although, the continuity of the sessions occurred on the same schedule as planned from the beginning.

Session 1

Patricia

Patricia participated in the summer camp vacations organized by the hospital staff. For, we had to reschedule two consecutive sessions with her. In her first session, Patricia, entered in the room shy, holding her father's hand. Curiously, she inspected the room, and her eyes posed immediately on the table full of colors and papers. Safely, she left her father's hand and sat on the chair. Without, using any word, just with a simple look, she invited me to join her on the table. Her father, left the room shortly, after making sure, Patricia was comfortably settled in the room.

The first interaction with Patricia was very short. She was more interested drawing then talking. I invited Patricia to join in the first session, after describing the task for the first session. On the table, I reached for a white paper and put 12 colors in front of Patricia. She immediately took her sweater off and posed her hands on the table showing her readiness. We drew six empty circles (representing faces) and gave an emotional expression to each one of them. Patricia was didn't want to give more emotional expressions and we started with the one on the paper.

I- Patricia, now these faces don't have any color. Would you like to choose one color from this set for each of the faces?

Patricia- Can I choose any color that I want?

I- Yes, you can choose the colors that you want.

Patricia- I will start with the happy face. Did you know that I was on vacations this summer? I went to the swimming pool. I made a lot of friends.

There was no hesitation on the “Happy” expression coloring it with yellow color. The hospital Santa Maria, every year organizes vacations for some children. The nurses and other hospital staff, followed the treatment in the summer camp. Her eyes sparkled when thinking of the vacations. She immediately, without waiting for my question, commented

> *"I'm happy when I think that I am going for vacations. I like very much the sun and the sea. My father is a little worried because is the first time that I'm going without them, but I will be with friends from the hospital. I know them. ….. We will eat good things, swim. Ummmmm I don't know to swim, but I will learn…… Sometimes my arms hurt, cause I want to go far.”*

While talking she was smiling, remembering the moment from her vacations. Her hand was going up and down coloring with yellow the face on the paper, and only when she finished telling her story, she realized her hand was still on the paper.

> *“I like yellow. It’s like the sun…… I like the sun because I go to the sea. And I like swimming.”*

She didn't have any problem finding the color for the other emotions surprised, tired, and worried.

Patricia- I remember only one time I was surprised. But it was a good surprise.

R- Do you want to share it?

Patricia- (paused for 1 minute) Yes, I can tell it. I was at home watching television when my father came home. He hasn't been home for many days. He came from work, and my mother didn't tell me because wanted to be a surprise. I was looking at him, but I felt like I was dreaming.

R- How long was your father gone?

Patricia- Two days

R- Do you like to spend time with your father?

Patricia- Yes a lot.

R- What do you usually do together?

Patricia- We play with video games, we play with cards, also he teaches me how to swim.

R- And today you came with your father at the hospital

Patricia- I always come with my father.

R- Do you like his presence here?

Patricia- I don't know. I like when I am with him.

R- Do you remember any moment when you felt good that your father was with you at the hospital.

Patricia- (Pause for 2 minutes) It was when I had to do an injection. I hate needles. I always like to hold my father's hand. He holds my hand tight, and I feel he is there.

Patricia chose orange when being tired. Her tiredness is immediately related with the hospital waiting hours.

> *"I don't like when I wait so long at the hospital. I want to go to school, but I have to lose one day at school because I am here."*

She didn't want to talk more and stood up to look around the room. Didn't say anything but just looking at the window. It was sunny outside, and she was lost in her thoughts.

Patricia- I like the sun. Can I tell you a secret?

R-Sure

Patricia- I like this room.

R- I like that you are here.

Patricia- In that other room there are so many children. It's very noisy.

R- What else you don't like?

Patricia- There is very noisy. And when the doctor enters the room I am worried that is my turn for the needle.

R- And what do you do when the doctor enters the room?

Patricia- I hide. So that she (doctor) doesn't see me.

R- Did it help you?

Patricia- No. She (doctor) always finds me.

R- And what do you do when she sees you?

Patricia- I hold my father's hand….. You know? I like this game. Can I fill with blue the next face?

R- The next face is "worried"

Patricia- Yes I want to be blue

R- Then you have to pick the color.

Patricia- Oh I already told you when I am worried.

R- It's the moment when the doctor enters in the room?

Patricia- Yes. ….. You look me in the eye.

R- Does it bother you?

Patricia- No. I thought that if she (doctor) looks me in the eye, I would know when is my turn.

R- And where does the doctor look?

Patricia- Nothing.

Agitated she finishes the conversation, filling the space with blue, tightening the pen very hard on the hand. She took around 6 minutes to think for the color to put on the face correspondent to the "sad" emotion. Continuously, she was looking at me for any suggestions. Her hand was always searching for the light blue.

“I feel sad when my father can not come at the hospital. Sometimes he has to work, and he brings me here and leaves me to stay with my brother. My brother plays with his phone and doesn't talk to me."

R- Do you hold you brother’s hand when you have the injection?

Patricia- No. He doesn’t look at me.

R- Did you ask him to hold your hand?

Patricia- No. He doesn’t like me.

R- Why do you think he doesn’t like you?

Patricia- Because he is old. He goes to school, and he misses school when he has to be with me.

R- And what do you do when you can’t hold anybody?

Patricia- Nothing. I don’t want to cry because my brother thinks that I am weak.

Patricia rushed into the next face. Her most interesting interaction was the moment of describing "Angry" with the red color. She put a lot of energies in it and already channelizing the accumulating anger in the face expression. As also seen a little from the drawing, she colored the face several times, without stopping, till she felt that the paper was going to tear. She didn't want to explain at once, took some time to think and out of a sudden, burst out:

“*I hate that I am the youngest of the family. My father takes my brother wherever he goes, and not me. I know that he thinks that I might be sick, but I won't…. It's the same as being at home. Right? ….. Well …. My mother thinks that I get flu very easily, and she puts me a lot of clothes on. Now I am sweating, but I can’t take this sweater off. Ufffaaaa!”*

After finishing all the faces expression, Patricia was looking at the papers and the color.

Patricia- Can we do this everyday?

R- Patricia, you come here every 15 days. Did you like it?

Patricia- Yes. I like to draw, and I like colors.

R- What do you like to do next time?

Patricia- I like to draw more things.

R- Can you mention anything?

Patricia- I don't know. Now that I am at school we don't draw so much. I like to draw a house.

R- I will think of your suggestions, and we are going to draw more things next time.

Patricia before going helped to put the colors in the case and arranged the table. Then she put the sweater on and opened the door. She longed her hand to hold mine till arriving at the "Sala des Actividades" where her father was.

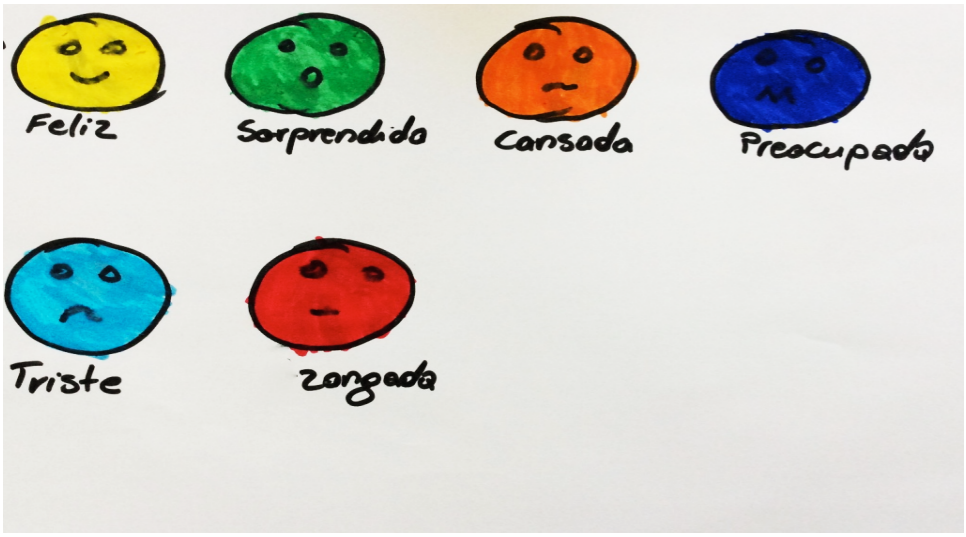

Figure 1. First art session, Patricia 7 years old, facial expression

Ricardo

Differently from Patricia, very careful and attentive in coloring inside the black line of the face, Ricardo had trouble to fill the faces. His hands sometimes were losing the control, like a sudden impulse and he urged outside the line. At first,

he was looking at me whether I was going to comment or say something, but when he perceived my silence, continued to comment:

> *"Usually when I do like this, my friends at school gets scared. I feel bad, but I can't control it…… Sorry that I ruined the face (smiling)."*

Ricardo was so happy to remember his memories. One of the most important and beautiful day was when his father brought him to the concert of his favorite singer.

Ricardo- A happy moment!

R- Yes. One happy moment

Ricardo- The happiest day was when my father bought me a ticket to the concert of my favorite singer.

R- That is very beautiful. Who is your favorite singer?

Ricardo- David Carrera. Do you know him?

R- I don’t think I do.

Ricardo- Wait, I can sing something for you.

Ricardo started to sing for five minutes looking at me puzzled if the music would sound familiar.

R- This is a beautiful song. Thank you very much for singing it for me.

Ricardo- I don't sing well, but I know all his songs by heart.

R- I liked your singing. And maybe you can show me some of his other songs for the future sessions. What do you think?

Ricardo- Oh really? So good! I will prepare the song before coming to the hospital.

On the paper, he wanted everything to be organized but felt bad whenever the color was getting out of the border. Then we continued with the Sad face expression. He didn't know what color to put on the sad face and was looking at the colors on the table. Then he picked the dark blue and stood for a moment.

Ricardo- I think blue is the right color when I am sad.

R- Do you remember any sad moment?

Ricardo- I have a lot of them

R- Can you tell me one sad moment?

Ricardo- Let me think! Hum… I can mention one. It was the day when I came at the hospital, and the doctor told my mother the treatment was not going very well. That day I was wearing a blue shirt, and now I don't want to wear anymore that shirt because it makes me sad.

R- Is that the reason you also picked the blue color for the face expression?

Ricardo- Yes. I mean, I like blue but when I think blue shirt I immediately think of that bad news I got at the hospital.

Ricardo needed more than 3 minutes to fill one face expression on the paper. His hand was trembling, and sometimes he was losing control over the paper.

Ricardo- Tired I get most of the time. When I walk, when I am at the school writing. My hand gets tiring very soon.

R- Do you like to make a pause?

Ricardo- No, I am not tired now. I feel more tired when I try to rush to catch the others and not to feel alone.

R- Can you tell me one moment that you remember?

Ricardo- Well, at school for example. When the teacher gives us exercises, I know most of them, but I can't write fast. So everybody finishes, and I am the last one. I know all the exercises, but I can't be the first to show cause I need more time to finish.

Ricardo tries all the time to follow his sentences with a smile. “Angry” expression for him was not a very important moment cause he doesn’t like to get angry. But he mentioned one moment when he felt angry.

> “*My family gives me all the things, especially my father. I don’t get angry with them. I can get angry when sometimes I can’t do something… I can’t play football, but that passes …. Especially after watching a match of football with my father.”*

Although being "tired" most of the time for him was a big problem. His legs and his arm get tired very easy, and he can't finish an entire activity. Even sometimes when he is walking to the hospital, his father takes a taxi when he can’t continue any more. This attention makes him also feel “sad” as he mentions:

> “*My parents already spend a lot of money on me, on my treatment, physiotherapist and I feel I cost them too much*."

R- Did you ever hear your parents complain about this thing?

Ricardo- No. They don't. But I feel in their eyes when they are tired or worried about me. I am a burden.

R- Do you feel like a burden?

Ricardo- No. They are very helpful and try to make me feel good.

R- I see you are massaging your hand. Do you want to rest?

Ricardo- No

R- But I like to take a pause and talk about something else. For example, the next expression is "Surprised." Do you remember any moment that you received a surprise?

Ricardo- Yes one surprise.

R- Do you want to share it?

Ricardo- Yes. My father took me for my birthday to meet the team of the Sporting football club.

R- Do you like Sporting?

Ricardo- Yes, they are my favorite. They are the best. I think this year they are going to win.

R- And how was your experience when you met the football players?

Ricardo- I will never forget it. It was beautiful. I talked to them; I took pictures with them. They signed my shirt.

R- Your father did a very beautiful surprise for your birthday.

Ricardo- Yes he always brings me to the stadium to watch the match.

R- He loves you so much.

Ricardo- I love him too.

R- He really wants to show you how much he cares about you. Don't you think so?

Ricardo- Yes he does. He always makes beautiful surprises for me.

R- So what color shall we put this expression?

Ricardo- I will put the blue.

R- This was a happy moment for you when you were surprised. Did it have any moment when you felt sad?

Ricardo- No. Well, a little bit because I can't play football and I wanted to play with the football players. But I chose the blue because I like it as a color.

On the last two Worried and Indifferent he chose two dark colors. For the worried expression, he didn't know whether the green would be suitable but then after a while; he filled the face with the color.

> *"Green is the color of Sporting. My favorite football team. It's not exactly this green, but I like to think of them. I know that I put it on the worried face expression but when I am afraid I think of them, and the way they fight, even when they lose."*

Ricardo- I will put black for the indifferent.

R- Do you like to explain it more?

Ricardo- Because I like to be indifferent to things but my parents they don't let me.

R- How is being indifferent to you?

Ricardo- I like to be alone for example and in my room. I don't stay all day. I like to be just alone. But my parents don't let me.

R- Did you tell your parents what you want.

Ricardo- They are worried why I am alone and ask me all the time.

Figure 2. First art session, Ricardo 14 years old facial expression

As he would press the color very hard on the paper, the characteristic of the face expressions fainted, reason why in some of the faces he didn't fill entirely with the color. During one hour we had to pause three times to do exercises for his hand. In front of the window there was the Sporting Stadium (his favorite sports team) and his eyes were always looking from the window. At the end of the session before going, he turned to me asking:

Ricardo- Will you be here the next time?

R- Yes. Did you like it?

Ricardo- Yes, this was nice. I will prepare another song of David Carrera.

R- I would like it a lot. Thank you.

Ricardo- Thank you!

Ricardo had some difficulties to stand up at first. He approached to the window staring at the stadium left the room confident with a big smile in his face.

Luis

Luis came into the room with his mother. He entered without hesitation, sat on the chair near the window and didn't look around to explore the room. His mother left, signing him, she was going to stand outside waiting for him to finish. Luis didn't say anything just looked down on the table and then looked at me.

After explaining the procedure of the session, he wanted to add some more expressions. He was very quiet and didn't want to exchange conversation. Looked at the colors and picked the black color to fill the first expression. Immediately after filling the "sad" expression with black, he said:

"…..You know what? I want to put some other faces."

He took another paper and drew new face expressions adding "Indifferent," "dreamer," "frightened." All the three of them have an interesting connection. Luis kept quiet while drawing. His replies were short nodding followed by a "yes" or "no."

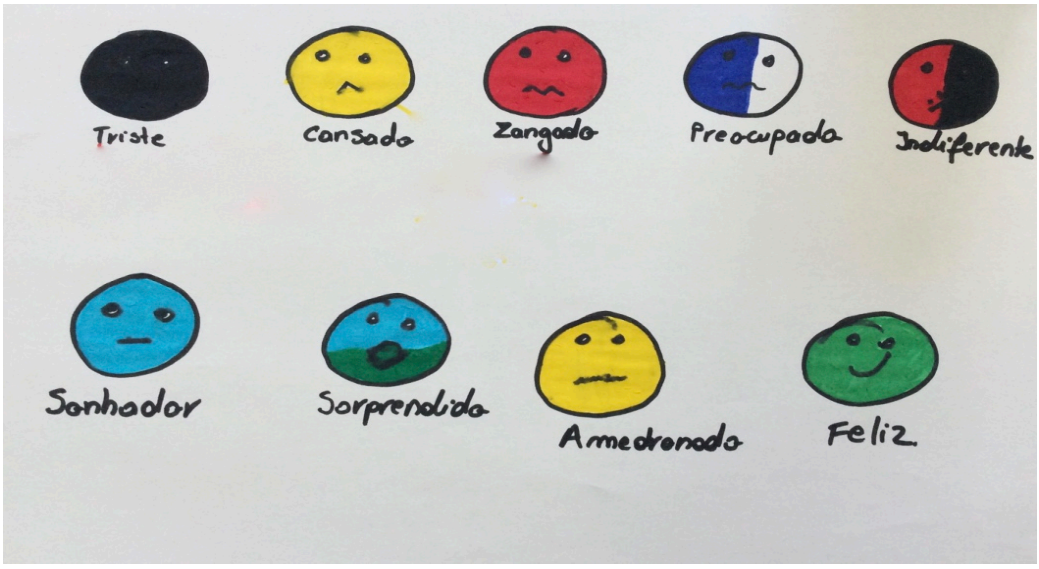

Figure 3. First art session, Luis 12 years old face expression

R- Luis do you remember a moment when you were sad?

Luis- I don't remember.

R- I see you put the black color. Does this color mean something to you?

Luis- …. I don't know…. It was closer to my hand…. Well, my mother dresses in black.

R- Do you like this color on her?

Luis- No. It's black!

R- What do you mean "it's black."

Luis- It's dark.

R- Does this mean that black makes you sad?

Luis- Maybe.

Luis stayed in silence and started to fill all the face expressions with one color. He didn't take his eyes out of the paper. Just for one moment, he looked in the direction of the window.

Luis- There is the Sporting Stadium in here

R- Yes, are you a fan?

Luis- No. I don't like Sporting. I like Benfica. They are always winning.

R- Is that why you like them?

Luis- Yes. Every year Benfica wins.

R- Do you watch the matches?

Luis- Sometimes, when I have time.

R- What is the color of Benfica?

Luis- Red (smiling)

R- I see that you have put red with an angry expression. Does this mean that you are a little angry at your team?

Luis- (smiling) No. I am not angry at them. I didn't think of them when I put the color

R- What were you thinking about.

Luis- Of today.

R- What is it today?

Luis- Nothing. Just I am angry today.

The conversation with Luis was not flowing. He didn't like to share his ideas and thoughts. He liked to be quiet and just finish his task.

Luis- Can I leave on half one face?

R- which face?

Luis- The "worried" face? I don't like to fill it with one color.

R- Of course. You can use the colors you want.

Luis- I will just put one color and leave the other half white.

R- Where you worried when you came in this room

Luis- No.

R- This room is quiet, and has a huge window to look outside. Do you like it Luis?

Luis- Yes, it's better.

R- Better then what?

Luis- Better then the other room.

R- What would you change in the other room?

Luis- Make it quieter. There are so many people standing there

R- How long do you stay in that room?

Luis- Almost one day.

……..

R- Today is Tuesday. Did you have school today?

Luis- Yes…… (pause 2 minutes) …. And I am angry.

R- Because you missed one day at school?

Luis- Yes

R- Was it a special day at school today?

Luis- I play football at school. Today we have a match.

Luis finally started to open and talk more about himself. After this conversation, the colors became brighter, and he was showing more interest to the task. His new face expression "dreamer" were very interesting and I was motivating Luis to describe the faces and his emotional connection with the colors.

> *"I like to dream. I mean not when I am at sleep. I want to play football, and I want to be rich. I want to be independent."*

Luis put his color down and stood up. He went close to the window and was staring at the stadium.

Luis- I have never been at the stadium.

R- Do you like to go?

Luis- Yes. Everybody wants to go to the stadium.

R- Do you like to play football?

Luis- Yes a lot

R- What do you think is stopping you?

Luis- My legs

R- Your legs? Can you tell me more?

Luis- My legs hurt. I can't run fast.

For the first time, Luis started to talk and verbalizing his ideas. His anger was becoming clearer now that he found the courage to talk.

Luis- Will you promise me not to tell anybody?

R- You don’t want me to tell anybody

Luis- Well this is not a secret. But I don’t want them to know that I am weak.

R- Them? Who are them?

Luis- My mother and my grandmother. I am the man of the house, and I have to be strong.

R- You said you are the men of the house.

Luis- Yes, my grandmother always calls me the man of the house.

R- And as the man of the house, what is your role?

Luis- I have to take care of them. To protect them

R- How can you protect them?

Luis- If I become a football player I can be rich and give them what they want.

R- What do they want?

Luis- Things, ….. clothes, ….. food

R- And what does Luis want?

Luis- To play football.

Luis has moments when he wants to talk but then closes into his own shelf and doesn't like to talk anymore. He just focuses on the paper and continues to combine colors for the same face expression. The peak of the session arrived when discussing the "frightened" emotion. He didn't say anything at first, and then he confessed:

> “*I don't remember….. (pause 5 min), but I can say one. I was alone at home and started to have pain and didn't know what to do. My mother was not there. I thought I could take a pill, but my grandmother doesn't leave them in a reachable place. I thought I could watch some TV, usually when I have the flu, when I watch TV I forget the running nose, or the pain in the throat. I turned on the TV, but couldn't focus. I*

thought what if I never had this pain and be like everybody else…… I felt scared cause I thought I would never be like that".

When the time was over Luis was still talking. He was looking at the clock. There was a door knock, and Luis immediately stopped talking. His nurse came to pick him up for his medication.

R- Luis thank you very much for your time. I liked your imagination. You are very talented.

Luis- Thank you!

R- Do you like to meet the next time you are coming to the hospital

Luis- Yes

R- Do you have any suggestions for the next time

Luis- I want to draw more

R- We will draw more next time.

Alex

Alex came at the first session alone. He had his headphone listening to music with high volume. He entered the room and immediately sat in the chair without looking around or paying attention to my presence. His head was down, and his eyes were closed. I tried to talk to him, but he didn't hear me. I sat next to him so he could acknowledge my presence. He looked at me and didn't put the headphones down. This silence continued for two minutes. Then I reached for a paper and arranged the colors on the table. He saw what I was doing and when our eyes crossed he immediately looked down. I took a paper and started to draw on the paper faces with different expressions. Then he looked at my work and lowered the music.

R- Do you like to help me?

Alex- What are you doing?

R- I am going to make six face expressions. Can you name them?

Alex- That’s easy.

R- Yes it is. Let's see how easy can you find these expressions.

He started to name all the expressions, and when we finished, he thought the job was done and was ready to put the headphones on.

R- Do you like drawing?

Alex- I don’t know

R- Why don’t we try it?

Alex- What should I do.

R- You have 12 colors on the table. Can you fill each of these faces with one color?

Alex- Yes. Only one color?

R- It’s your choice how many colors you want to use.

Alex started to fill the face expression without commenting anything. He tried to fulfill the task being annoyed and at the end left the colors on the table, staring at me waiting for the next task.

R- Which is your favorite color?

Alex- Green

Me- I see on the paper you have used the green for the "tired" face expression. Was it a choice at the moment?

Alex- No.

Then he stood up looking around the room and putting the music in high volume again. He walked around for a few minutes then sat near me.

R- Hello. Can I talk to you?

Alex- (turning off the volume) what?

R- What kind of music are you listening?

Alex- It's regaton. Do you know it?

R- I've heard of it. Do you like to show me?

Alex- It's a very intense music.

R- Strong music?

Alex- Yes for dancing

R- I would like to hear something

Alex- (unplugging the headphones to play the music) This is regaton

R- Do you dance as well?

Alex- No. But I like to sing

R- That's fascinating.

Alex- My mom works in a club. They play Regaton all the time

R- Do you visit your mother at her workplace?

Alex- Yes

Alex was indifferent at the beginning of the session but after we started to talk about the music he became open to the conversation. When discussing the happy moments, Alex commented:

> *"I like to go to the club my mom works. There I can hear the music, and my mother gave me this MP3 so I can listen to Regaton all the time I want. I am happy there. At least I don't have to be here at the hospital. There are so many people, and they treat me like a grown up. I am happy there…….. Oh yes, I used the blue color. It's because the club is painted in blue, and it reminds me when I am there."*

Alex doesn't like to talk about his health condition, and in most cases, he avoids the questions by turning the conversation into music. He can talk for hours about his favorite singers, and also the titles of the songs. The first part of the session leaned on the music topic. Afterward, Alex started to open more and talk about himself.

When he was ready to talk about the “sad” expression he looked at me as trying to understand if I was going to betray his trust.

Alex- I like to dress in black.

R- I see that you used the black color with the sad face.

Alex- (smile) yes, because I am sad most of the time

R- What makes you sad?

Alex- Everything

R- Can you tell me one thing that makes you sad?

Alex- Coming here at the hospital makes me sad

R- What are the things at the hospital that make you sad?

Alex- I am alone here

R- Are you alone?

Alex- Yes, my mother is never here. She goes to work. She just brings me here, and I stay here alone till the afternoon.

Every time Alex comes to the hospital, his mother leaves him with the educators of the hospital, and she rushes to her work. The educators try very hard to talk to him, or to have his attention but he resist, and they always refer to him as a "wall."

> *"I am worried when I have to come at the hospital. I will stay here the entire day. And sometimes I am tired. I want to sleep. I don't know anybody."*

Alex collaborated a lot on the second part of the session talking more about himself, and it came the moment to speak about the "angry" expression he felt open to reveal what exactly was making him angry.

Alex- I am angry at the hospital.

R- Who you are angry with?

Alex- With anyone. They treat me like a baby. They want me to talk

R- Why do you think they want you to talk?

Alex- Because I like to be alone.

R- Do you really like to be alone? In the hospital, they do a lot of events, drawings, singing, games.

Alex- I don’t like them.

R- Have you told anybody what you like to do?

Alex- They don’t understand. They just want me to play.

R- Maybe that’s why they want you to talk. They want you to say what you would like to do.

Alex- I don’t like it.

R- And this makes you angry.

Alex- Yes

R- You have putted the red color for the sad feeling.

Alex- Yes. My teacher when she gets upset at us she gets red. And I think that red is angry.

Alex starts to open, but when he can't give more arguments to explain his ideas, he closes himself and tries to be the strong and angry boy. Although, the situation in the hospital is not easy for him, he is always alone, and during the day he wants to have the presence of someone he trusts. His need to be angry with his mother doesn't permit him to socialize and communicate with the educators.

Figure 4. First art session, Alex 12 years old face expression

Alex almost at the end of the session asked if I wanted to listen to another song. He showed me a new regaton song. During the 2 minutes of the songs, he was pausing the MP3 to show me the lyrics, the singer and other details of the song. At the end of the song, he stood up to leave. He putted his headphone with high volume and with a very light smile closed the door.

Eleonor

Eleonor felt scared to enter alone at the room. Her father was at the hospital with her. She was holding his hand tight and looking down biting her thumbnail. They entered together. Her father told Eleonor that he was going to be outside waiting for her, but she didn't leave his hand. I suggested that her father could stay for a while in the room and when Eleonor would feel safer her father could leave. She accepted, and she waited first her father to sit, and then sit next to him.

On the table, I showed her the papers and the colors. Also, I explained what the task for the first session was. Her father rushed saying that his daughter likes to draw and likes bright colors. She always dresses with light colors. Eleonor was looking at her father waiting for his suggestions. I started drawing on the paper the faces and asked her what were some expressions she would like to draw. We began with the happy expression. When I asked her to chose a color and fill the face with that color of choice, she looked at me puzzled, then looking at her father for suggestion what color to chose.

Eleonor was very shy and was speaking in a very low voice. Her father would rush to explain everything she was saying and in many occasions to repeat her words. For the first expression, she spent 5 minutes to chose one color. Anytime she would choose one would look around for approval. She didn't have any approval from me, and her father would suggest her sometimes a color, afterward, she would change it again. I intervened telling here that she could mix colors for one expression. She chose the orange color and started to color just half part of the face. This procedure took more than 1 minute.

Eleonor's father saw that she was understanding the task and kissed her to show his presence. She finished with the first color and then picked the light blue to fill the other part of the face. After completing this procedure, she looked at me.

R- Eleonor, now we will do the same with the other face expressions. You can choose one color you like and fill the face. Can you do that?

Eleonor- Yes

R- Good. Do you think we can let your father go? He will stay right behind the door, so when we finish, you can meet him again.

Eleonor’s father- Yes, I will be behind the door. Sited in the chair and will wait for you.

Eleonor- (paused for 1 minutes) Go.

Eleonor's father left the room, and she felt shy and started to bite her thumbnail.

R- Eleonor, do you like to choose another color for the other face. Now we have the "sad" expression.

Eleonor- I can!

R- What is the color you want to choose?

Eleonor- I don’t know.

Eleonor waited for 4 more minutes to chose the other color. We had eye contact, and her eyes were asking for one color. I stayed static and didn't give her any suggestions.

R- Do you remember a moment you were sad?

Eleonor- (smiling) No.

Me- You are never sad?

Eleonor- No

R- Were you sad when your father left the room

Eleonor- Yes

R- So we have a moment when you were sad. Do you have a color that is sad?

Eleonor- I don't know….. Gray?

R- Grey. Can you find the gray color?

Eleonor- Yes

R- Good. Can you fill the face with gray?

Eleonor- Yes.

Eleonor started to fill the face with the gray color. She stayed in silence. She didn't want to comment anything about any moment when she was sad. But when asked about the gray color she said:

"Gray…. It's a sky with clouds. It's sad when the sky is gray."

She started to bite her thumbnail again and looking for the next suggestion. The next face was the surprising one.

"I was surprised when my mother told me I was going to have a brother soon."

Eleonor's mother is expecting her brother, and in one month they will have the new baby home. Eleonor brushes when she talks about her brother to come. She put the purple color on the surprising face. She didn't tell much about her choice of the color but in one moment just mentioned:

"I…. Maybe I will like my brother…. I… will share… my room with him"

Finally, as the time was running fast while Eleonor would take her time to chose the color, she was getting more comfortable to fill the faces on the paper. For the last face expression "Tired" she mixed two colors the green and the brown. At the beginning she was thinking to fill all the face with green, then at a certain moment she stopped, paused for a moment and then took the brown color and filled the other half.

R- You chose two colors for the last face

Eleonor- (smiling) Yes

R- It's a green and a brown

Eleonor- Yes? (puzzled from my intervention)

R- I like your combination. It is very beautiful

Eleonor- I like the green

R- Do you remember a moment you were tired?

Eleonor- (shyly) I don't remember

R- What about the brown color, do you like it?

Eleonor- No

R- Your father said that you like colors and that you like to have colorful dresses. What color would your dress be if you were tired?

Eleonor- I don't know…. Maybe…. Green

R- Green. The color you like

Eleonor- Yes……and brown

R- Both of them?

Eleonor- Yes

R- I like it, it's very interesting.

Eleonor- I like colors.

R- What is the color of your dress when you come to the hospital?

Eleonor- Dark blue

R- Do you like this color?

Eleonor- Maybe… I don't like it a lot.

R- If the dark blue was a face, what would that be?

Eleonor- I don't know…. I don't know…. Maybe angry

R- Do you want to draw it on the paper?

Eleonor- No

R- Then, tell me are you angry when you come at the hospital?

Eleonor- A little bit (smiling)

R- Who are you angry with?

Eleonor- I don't know. No one.

R- Your father today was wearing a shirt with the dark blue

Eleonor- Yes. I chose it for him

R- Are you a little angry with your father?

Eleonor- No…..Maybe ….. a little

R- Do you like to tell me why are you angry?

Eleonor- (smiling) I am not any more.

R- Good. So now is not important. Now it's gone. But what made you so angry?

Eleonor- (biting her thumbnail) I wanted to come with my mom at the clinic

R- You wanted to come here with your mother?

Eleonor- No, I wanted to see the baby at the clinic where she goes

R- Oh today your mother was going to see the baby. (echography) You wanted to go with her, but your father wanted you to come at the hospital today.

Eleonor- Yes

R- Are you angry at him every time he takes you at the hospital?

Eleonor- (smiling) Not anymore.

The time for the session expired, and Eleonor's father was waiting outside so she could start her treatment. At the end of the session Eleonor collected all the colors and gave them to me. Afterwards, she was studying my behaviors if I was going to talk to her father. When she saw that I opened the door for her and said goodbye to her father she stopped biting her thumbnail and waved her hand to say goodbye.

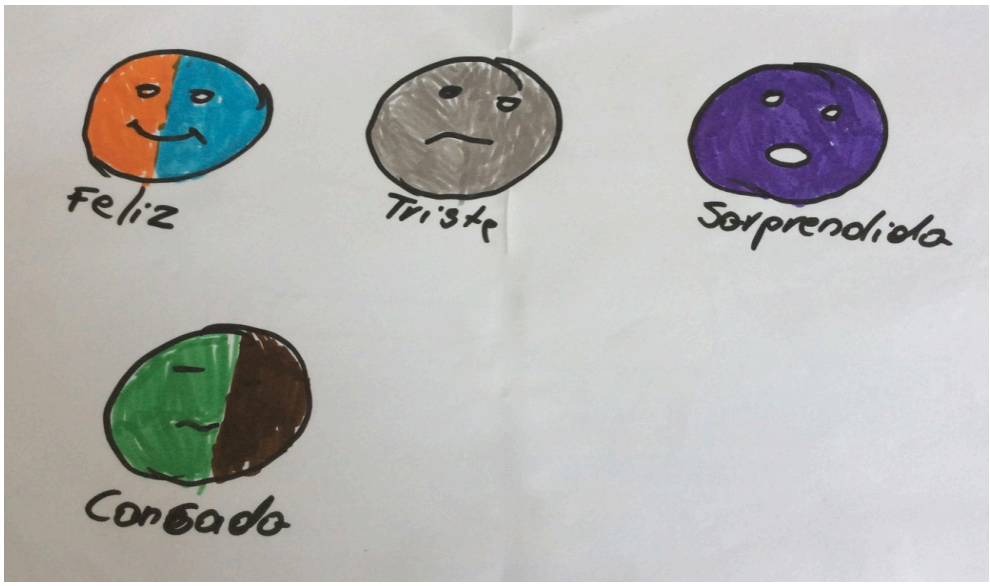

Figure 5. First art session, Eleonor 9 years old face expression

Vanessa

Vanessa came with her mother at the session. She entered the room and sat on the chair. Her mother wanted to stay inside the room. even though, one week ago she accepted the conditions of the sessions. The first five minutes of the session I explained Vanessa's mother the room conditions and the materials (already disposed one week ago at the meeting with the educators). She was skeptic and needed to see better the room's conditions. After a while she

decided to leave and counseled Vanessa many times, she was going to stay right behind the door.

Vanessa- I am sorry, my mother sometimes is very annoying.

R- It's fine. She is worried about you and has her right to know more about this session.

Vanessa- Yes but she is extreme

R- What do you mean "extreme?"

Vanessa- She doesn't let me alone not even five minutes. Always behind my back.

Vanessa rushed explaining her contradiction with her mother, explaining that their family has Egyptian origins and her mother is very conservative.

> *"I am tired of her. I am 16 years old, and she doesn't leave me alone, not even for 5 minutes."*

After showing the first task to Vanessa, together we decided to choose the face expression she wanted to show. We started with the happy face. Differently, from the other cases, Vanessa refused to color the entire face. She decided to color the eyes of the faces and their mouths with different colors. On the happy face, she posed the light green color on the eyes and the red color on the mouth.

> *"I always wanted to have green eyes, but my eyes are just average… brown."*
>
> *"A moment when I am happy?.... I don't know, they are very few…. But the moment I am happy is when I go to the church. My mother trusts me when I am there, and she doesn't follow me."*

Vanessa focused her conversation about her mother. When coming to the "sad" expression, she just needed to remember moments when her mother made her feel sad. As a teenager, Vanessa needed her privacy, and her mother was very protective of her and following her everywhere.

> *"I am sad when I have to go to school every day, and my mother is there all the time. I can't stay a little bit longer talking to my friends."*

R- Do you feel sad when your mother comes with you at the hospital?

Vanessa- Well, here I can't come alone

R- At the hospital is better in her presence.

Vanessa- No, I mean I sometimes come with my father, or sister. But they are busy, and my mother is free. So she comes more often.

R- How does her presence in the hospital make you feel?

Vanessa- She doesn't let me talk to the doctors or educators. She controls everything I do.

Vanessa had a burden, and she found a way to talk further about her mother. Then I needed to direct the conversation more health related and on the third face expression "Surprised" she talked about her health situation. Vanessa when she was little enjoyed the attention that her parents and her siblings, but then when turning into adolescence she needed freedom.

> *"To have more freedom, I joined Evangelic church near my house. There I meet many people that accepted me, and I didn't listen so much to what they were saying, but I liked the fact that this church found a job for my father and helped my sister have a wedding party."*

Vanessa was going to the church every weekend, and with the passing of time, she does not like it anymore.

> *"I was surprised when my mother trusted me on the medications and to control my disease. I know that what I have is not dangerous. I had it since I was very little so now for me doesn't make a lot of difference."*

Vanessa craved for independence, the freedom to control her disease. Her health situation was not sometimes was an excuse her mother used to control her. Vanessa has to be very careful with her diet and medication.

R- Do you remember a moment you were angry?

Vanessa- Yes, I do!

R- Do you want to share it?

Vanessa- Sure… I was angry when my mother didn't allow me to talk with the doctor about a problem I was having. She interrupted me all the time.

R- What did you do when this thing happened?

Vanessa- Nothing, I let her talk. But I was furious

R- Did you speak to your mother afterward how did this make you feel?

Vanessa- No, she doesn't understand

R- The way you explained it to me was easy, and I did understand. I think if you use the same words, she will understand too.

Vanessa- Maybe. I will put the purple color. It's my mother's favorite color and I know that it fits her.

The time with Vanessa run so fast, and she also started to talk about the meeting in the church and about a boy she liked.

“I like to talk to him, but my mother can’t see me with him.”

Vanessa ended the session with three new expressions "Worried, exhausted, and silly." She also wanted to talk about the moment that she would feel silly around with this boy she was seeing. The first session served better as a bridge to gain her trust and also as a vessel to carry many of her burdens, mainly related to her mother. As a teenager, Vanessa likes to talk about her friends and new emotions. I didn't interrupt her need to speak about these topics. In the next session, these burdens are going to be consumed and focus on the health issues.

Figure 6. First art session, Vanessa 16 years old face expressions

Session 2

The subject of the second session was “Me” focusing on the body part and identifying the pain, this was very easy for each of them, mainly because the first questionnaire gave them more feedback how to identify pain.

Patricia

Patricia entered the room confident, running to sit in one of the chairs around the table. Her father gave her a smile and closed the door. Patricia was smiling looking at the colors on the table and also to the papers.

“What are we going to do today?”

She was very happy to draw and have all the attention for herself. After describing the new task, she immediately took the brown color and started to draw a person.

"I don’t know to draw very well."

She felt the need to explain her difficulties drawing as she was asking for forgiveness. Then she gave a smile and started to draw again. Patricia kept very tight the pencil on her hand and bowed very close to the paper. Her hands became to sweat and her eyes got tired from the beginning of the drawing. At some moments her glasses touched the paper, and she was smiling intimidated. After acknowledging these difficulties, the sessions added a new objective, helping to improve the posture while drawing. The glasses were heavy for her little face, and despite the lace on her neck, they would drop down easily. From the second session we discussed about this new objective and promised to work more on her body posture. Patricia agreed, and we agreed that she would repeat some of the exercises from the session also at home when doing her homework, but also at school.

She took a few minutes to think what to draw and staring at the paper holding the color on her right hand. Before starting she urged explaining:

“I have pain in my eyes. I am always tired and need to close my eyes. …… I told this to my father.”

Patricia explains having a strong tie with her father, trusting him, especially regarding her heath condition. Quietly she started to draw the first line on the paper and soon started to fill the head of the person with pink and immediately after red lips. The eyes on the drawing are small and black, clearly without the

glasses. In the end of the drawing there was the body of a person in in purple and the blue legs.

> *""I feel pain on my shoulder and legs. I don't like my legs. They are fat. And I can't run with my fat legs."*

Regarding the task of the second session, Patricia replied to the magic question "If one morning you wake up with no disease, how would you feel? How would your day be?"

At first it was difficult for Patricia imagining herself without the disease, as she has lived with this condition almost for her entire life. For, Patricia described another person she knew and she admires who doesn't have any disease. Her words were filled with jealousy but with anger as well, for her lack of chance to have that 'perfect' life situation as her friend in the drawing use to have. For a few minutes she stopped drawing and we started a little conversation about the other girl, Patricia would like to be.

Patricia- The girl that is not sick is Ana. She is in my class.

R- How does Ana feel?

Patricia- She feels very good! She has these beautiful dresses and shoes. She is very good in school.

R- How is one day for Ana?

Patricia- Ana goes at school in the morning. She sits in the first raw of the class. She takes only good grades. She has shiny hair.

R- What would be the color you would use to draw her?

Patricia- White, Ana always dresses in white.

R- And how is a normal day for you?

Patricia- I wake up early to go to school.

R- Where do you sit in the class?

Patricia- I sit in front because I can't see very well.

R- What else do you do?

Patricia- I don't have many friends at school. They want to play but ….

She didn’t want to end the sentence, at least not from the start. The other girl was one of her classmates. She considered herself "fat" and "clumsy." She is mostly absent at school due to her hospital visits and sudden flue symptoms. Ana was the girl everybody liked, but Patricia’s jealousy didn’t really have any tie with her health condition at first. Only, later she would explain her difficulties making friends and especially being friend with Ana.

> “*Yes, I sit in front row because of my eyes….. the teacher always asks me twice if I can see or not….. Then for the break, they run in the corridor and jump, and I can't follow. …. Ana is lucky. Her legs are thin, and she can jump. …. If I jump my glasses fall. My parents need to buy new ones. ….*"

Patricia was discovering details about the coexistence with the disease. She described her pain mainly related to her legs and the difficulties with her eyes. From a first looks like the problem with her legs was more aesthetic, although, when she describes her need to run and jump with her friends, the pain becomes clearer.

> *“If I was not sick, I could play with friends and not come here (hospital).”*

Patricia found amusing to walk around the room to distract herself or avoid uncomfortable thoughts in her mind. Quietly, for more than 10 minutes, she decided to walk around and turn once in a while to put more details in her drawing. Being diagnosed from an early age, didn’t give Patricia a chance to have an easy childhood, reason why at the end of the session, Patricia stated:

> *“I think that Ana would do the same if she had fat legs, and Ana doesn’t have to come at the hospital.”*

Before leaving the room, Patricia felt less anxious to talk about her body. She described the pain in her arms as well, especially how difficult it is for her to make fast movements. It was difficult to write and sometimes even to play. Patricia showed also difficulties to coordinate her eyes with the hands. Her arms are very soft, and she explained that even when she swims, she gets tired very

easy. At the end of the session she gave me a hug and a big smile then she run to meet her father waiting in the other room, and the nurses were preparing her treatment.

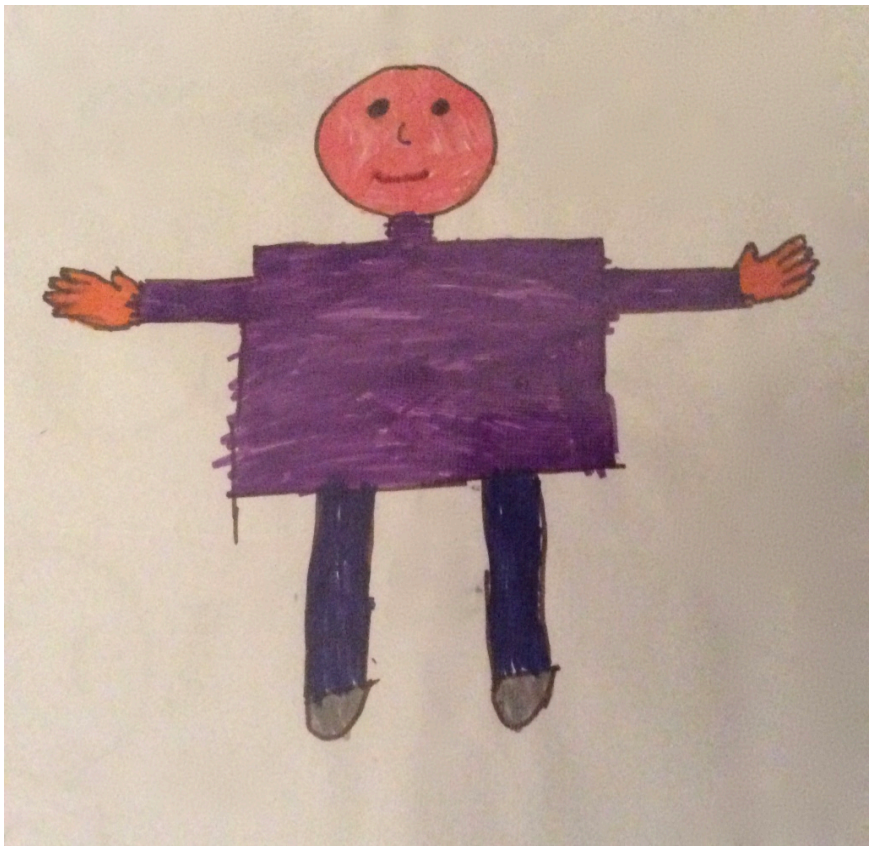

Figure 7. Second art session, Patricia 7 years old drawing of a person

Ricardo

Ricardo entered the room very tired. He explained that last night his family and relatives had a celebration that ended very late. His eyes were almost closed, but he couldn't help himself talk about the dinner and the party with his family, so with one breath he continued:

> *"My aunt likes me a lot. She brought me a big present. It was a wind up train. I immediately started to play with it. Then she told me so many new things about her trips and my cousins. My cousins are married and have children, so I see them only during these big events."*

While describing the dinner with his family he recalled the promise to prepare a song for the session from his favorite singer. He looked ashamed for forgetting the promise and lost the sleepy feeling.

"I didn't prepare the song but I know it very well, and I didn't forget it. So, I can sing it."

He started to sing and forgot his complexion how his voice would sound when singing out loud. Later on, he rushed explaining also the lyrics of the song, referring to a boy that liked a girl very much. He was following her step by step till she finally noticed him. To my question, if this song reminded him of any episode similar to his life, he smiled and looked away wanting to avoid the question. This episode made him less sleepy and asked me for the next drawing. I showed him the task, and he started to smile. The first drawing related to the magic question, imagining a day waking up without a disease he simply replied with this question:

"Can I have my name, Henrique?"

Ricardo didn't give any explanations who Henrique was, but he immediately chose the yellow color and drew the portrait of a person.

"Henrique is a happy boy. He goes to school alone and has many friends. He likes to play football. His favorite football player is Ronaldo. He likes to run. Sometimes he get tired, but he just need to eat whatever is in the fridge and get back to play."

He stood up and later went closer to the window to look at the Sporting Stadium. Didn't like to talk about anything just getting lost in his thoughts. After a few minutes, he reached his chair, followed by a smile asked for another drawing. The movements around the room, was also an exercise we planned from the first session to help him relax his hands. He requested to draw two different images, one for the person that doesn’t have pain or any disease and one to draw himself. When the moment to draw himself came, he started to complain that he can't draw very well. He used the yellow color for hid head. The task of the session was also to describe each part of the party with a specific feeling.

Ricardo- I am happy when I am at home. But I feel tired in my legs and body.

R- When do you legs and body feel tired?

Ricardo- I am tired most of the time. My hands also. I am angry with my right arm. I can't write, can't draw. But I am surprised with my left hand. I don't get tired with that.

> "*My right hand I feel surprised. I believe that it doesn't work as my fathers, and that really surprises me, because I do exercises every day, but I don't change. In my head, I am worried, most of the time, but I avoid to think. But my right leg is so sad because I want to make a goal when playing football with my father…. I want to make him happy. He shows to be happy, but I don't play like my brother."*

Ricardo didn't put too many details in his drawing. The face didn't have eyes, or mouth or any other details. When he started to draw himself, he got a little upset and nervous, wanting to finish the task as soon as possible.

> *"I am tired with all this. I have been coming to the hospital since I was little and still, I am here. …. Maybe …. I don't know how I can be like Henrique. Maybe…. maybe…. I will not know how to be like him."*

Ricardo had many repressed feelings about his disease and pain. He didn't feel very open at once, but around the end of the session, he started to open out little by little.

Ricardo- I have pain in my legs.

R- How long does the pain continue?

Ricardo- It never stops. But when I walk I feel it a lot. My parents have to bring me by car till here, cause I can't walk so far.

R- Your family is very careful.

Ricardo- (smiling) Yes they are. I love them very much. Sometimes, I think if I was Henrique they could have loved me more.

R- What would Henrique give them?

Ricardo- He can run, he doesn't need to come at the hospital. He doesn't have special food to eat.

Ricardo started to show his remorse for keeping his parents worried about him. His family is indeed very careful and tried the best to give him all the necessary attention. They organize every weekend picnics so that Ricardo can go out and meet with his cousins and friends. Ricardo conscious about their constant help feels unable to repay them with an energetic boy that can run, or swim, or play with his cousins. Ricardo finished filling all parts of the body with different colors. His hands would get tired very easily, and we had to stop the work many times and do some exercises till he could continue with the rest of the task.

Figure 8. Second session Ricardo 14 years old drawing of Henrique, imaginary person without a chronic disease

Figure 9. Second session, Ricardo drawing a person

At the end of the session, he finished his legs filling with blue. He misses the field of football very much and especially the lack of energy to run and play the game. Before leaving the room, he looked again at the stadium and then with a smile confessed that he can't be as Henrique, because he has never been different.

Luis

Luis entered happy at the room. He was very surprised his mother this time let him come alone at the room. He sat in the chair and didn't say anything. Replied sharp to my questions about the weekend and was looking puzzled to the papers and the colors on the table. After explaining the task, he smiled and said that he was not good drawing persons, but he would try to do a good one.

He started to draw a person, and regarding the task, he didn't want to talk at first. After finishing the drawing, he added:

> "*Ok … I can do that…. In my head, I feel more a "dreamer," "sad," angry"…. But here in my mouth I am mostly "surprised" Have you ever been surprised?..... I do most of the time. Because some things I can't explain and all the people tell me I am very little to understand. But I want to know…… They say I am grounded…What for?..... Ok maybe sometimes I take some bad grades at school but try not to be able to play football! I want to play football and. I want to stay longer with friends and I can't."*
>
> *"Sometimes I have pain, but when I am with my friends, I don't have pain. In my right leg, I am tired, most of the time and I feel numb, when I stay sited for a long time."*
>
> *"I like to play video games as my friends do, go to the cinema, listen to music. Most of the time I can't do them because my mother wants me to do my home works… If I was not sick, I would travel with my father."*

Luis had always felt that his father is missing because of his disease. He, believes that he can't go with him on long trips. He has a special diet, a special

medication and very often needs to come at the hospital. When he was explaining this situation, his eyes started to tear, but didn't say anything, just remained quiet and began to fill the parts of the body with different colors. On his head he urged saying:

> "*My head is sad, is worried, but most of the time is a dreamer. I like to dream about my trips, visiting new places. …. Maybe I will do them."*

He didn't like to talk a lot about his arms although from the drawings he showed that his arms are strong and he didn't feel any difficulties. He also helps his mother with the shopping bags. He always believed to be the man of the house and helping his mother.

> "*If I was not sick, I would play football and be professional. Also, I could play with Sporting club and have a lot of money to help my mother."*

Luis's biggest dream remained the one to become a professional football player, mainly because they earn a lot of money in a short time and this would make his mother proud of him. Unfortunately, with the health situation, he felt he didn't have the same advantages as other peers at school.

When filling with color the legs in his drawing, he briefly mentioned that on his left leg he felt mostly tired forbidding him to run fast, although, he didn't miss courage to continue play football.

> *"I am angry with my mother, cause all she cares is my homework."*

Luis was very clear in his description that football is the mean to achieve his mother respect and his independence. Unfortunately, he was not able to see other ways to reach his goal. The broken dream of becoming a football player was impeding him to enjoy other activities at school. Regarding the hospital visits, they were becoming the primary enemy as they prevented him from participating in the football matches at school and showing his talent.

Luis at the end of the session, decided not to talk anymore. He stared at his drawing and wanted to remain in silence. My question to share his thoughts, he just replied with a friendly smile and adding:

“Next time can I draw something else, something that I chose?”

His main wish was to be free and remained in silence until the end, and my approval to his request brightened his face. Luis gave me a smile and left the room.

Figure 10: Luis 12 years old drawing on the second session

Alex

Alex came again with his headphones on his head and immediately sited on the usual chair. This time he took the headphones away and lowered the music without waiting for my request.

Alex- I have a song that I want you to listen

R- Sure, I would like to hear it.

Alex- I think you will like this. I chose it yesterday for you.

R- What is it about?

Alex- It’s more music than text, but I like it. Can I play it?

R- Sure, please do!

Alex turned on the music and closed his eyes feeling the rhythm. It was a Regaeton song from his favorite list of songs. It lasted for 3 minutes maximum. Alex opened his eyes only at the end of the song and looked at me puzzled to understand my reaction.

R- I liked it a lot. Why did you choose this song for me?

Alex- I knew you were going to like it. I listen many times a day this song.

R- Did this song make you think of me?

Alex- Yes a little… I start to imagine when I listen to this song, and here when I draw I also imagine things.

R- What do you imagine?

Alex- Things…

R- Do you like to share any of these ideas?

Alex- I like to imagine like I can dance or sing this song.

R- And what do you imagine when you draw?

Alex- No, it's because you let me sing the songs and listen them with you. My mother doesn't like this music at all. She tells me to turn off the music cause she has a headache. I imagine the same when I draw

Alex briefly explained that his mother did not very well accept his passion for this rhythm and also in the hospital, the reason why he liked to stay alone without the presence of the other children. In the room, he found a place where he could share his dream to dance and sing.

Regarding the task he added:

"Of course I would be able to dance this song."

Alex believes that his sickness is stopping him from dancing. While drawing he added that the pain in his head makes him have vertigo and lose the equilibrium. This type of music requires a lot of spinning and he can't perform fast. Reason why, he prefers better to sit and listen to the songs and imagine how would it be to dance them. He never tried to dance, and his mother could not afford him to take any dance classes. At school, they don't have specific classes in this discipline, and the only place he feels close to his imagination is when going to the club his mother works. Alex enjoys seeing other people dance and has memorized some basic moves, but doesn't feel comfortable to try them, even when alone at home. His fear is to discover he is not good in dancing and give up definitely on regaton.

He started to draw the image of a muscular man. He refused to fill the parts of the body with a color but just used the borders. Alex has created this image of a healthy and muscular body keeping in mind the stature of a dancer. He also gave a name to the portrait.

> *"Pedro, is a boy that dances at the club. Everybody likes him when he dances and he can do whatever he wants… I like to watch him. I like looking at his feet…. He is really great."*

Alex turned talking about himself as trying to enjoy the music, but he knew that it wouldn't help him at all. He mentioned his mother feeling tired after her shift at the bar, and he was aware that as soon a possible, he had to help her somehow.

> *"She comes home tired, and I need to find a job to help her. …. This music is not going to help me."*

Alex wanted to take a break and showed me another song. He mentioned many other songs but selected one that Pedro dances. He closed his eyes again and started to imagine the steps of the dance. To my request to show the steps he smiled and looked through the window puzzled if he can do it.

> *"Can I do it the next time? I need to prepare the steps. I don't know if I am going to do that."*

Happy to hear my approval, he finished his drawing and stood up thinking about the space he needed to dance. He wanted to move the table aside to free the space and dance. Then he asked me if I could join to dance a little with him.

Alex- I will do it, if you promise me to dance a little with me.

R- Will this help you to dance?

Alex- Yes. I don't like to dance alone

R- Then, I will try my best to follow your steps. I am very happy we are going to do this together.

Alex- I am too.

At the end of the session, Alex left the room thinking of the song and the chance to dance. He totally forgot the injection waiting for him at the nurse room and was walking slowly down the corridor with his headphones and high volume, but with a light smile on his face.

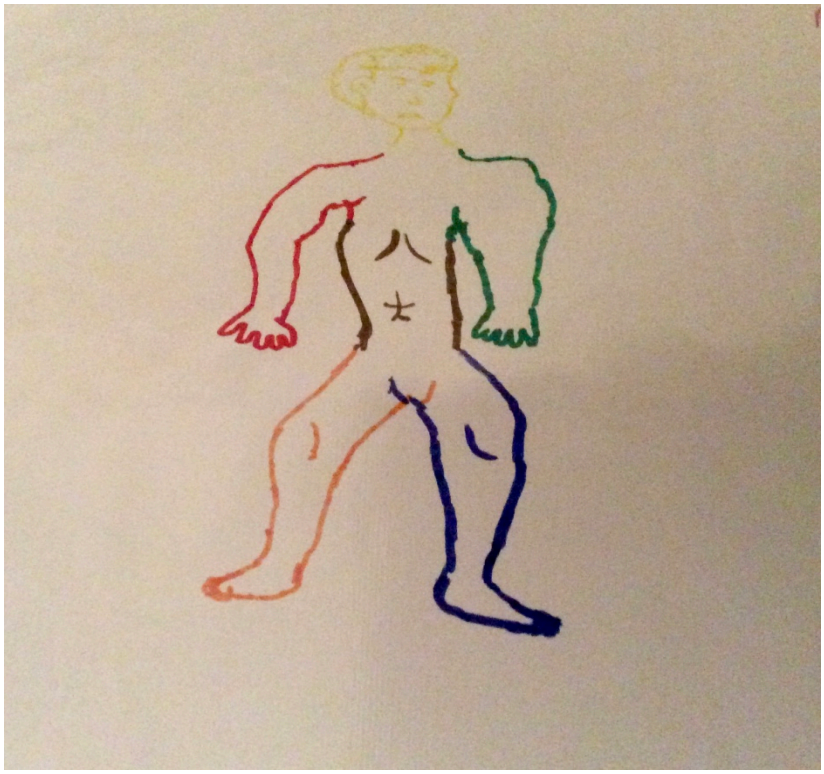

Figure 11. Second session, Alex 12 years old drawing of a person

Eleonor

On the second session, Eleonor came with her mother. Her mother was tired because of the hot weather and also the pregnancy. She brought Eleonor at the room and entered together holding hands tight. Eleonor sat next to her mother and once again she was shy to stay alone in the room. She started to bite her thumbnail and looked on the table.

Her mother requested to stay for a couple of minutes inside the room till Eleonor was ready to be alone. The approval made Eleonor happy and immediately stopped biting her thumbnail for a few moments. We started to talk about the week to encourage Eleonor describe her weekend. She refused to reply but was satisfied by just approving her mother's sentences. After a while, I introduced Eleonor the task of the session, and asked her to draw a person. When she started to draw, she forgot her mother was in the room, and soon after Eleonor's mother left the room without any resistance from her daughter.

When her mother left, Eleonor was a little confused with the task of the session. After explaining again she smiled and started to draw on the paper. Eleonor continued drawing quietly filling all the parts of the body with different colors and after finishing puzzled looked at me. The procedure took long as Eleonor didn't know what color to chose. When she found no suggestions, she took several second to pick the color and after a while change it again, till finally committed to use one. The face area of the drawing she divided it into 2 parts red and green. This division was mainly manifested from her insecurity to use only one color. Continuously, she changed colors and stood in quiet till the end of the task. At the end of her drawing she mentioned:

"I am happy today; I came with my mother."

Her happiness was clearly described in her drawing using mainly bright colors. In the first sessions Eleonor expressed that she likes bright colors when she is happy, and they manifest her emotional status. Out of a sudden she started to bite her thumbnail again, intimidated was looking around for the next task. Eleonor, didn't accept to talk, despite my continuous invitation to describe her drawing. At this point we continued with a new objective andn that was drawing

the magical question. Who would Eleonor like to be if she didn’t have any health problems?

This time it was easy for her. She took two different colors the blue and the red and started to draw a person. I was wandering if Eleonor would put a name to this person and she just mentioned

"Baby."

She was referring to the new baby her mother was expecting. That was an ambivalent of feelings. On one hand Eleonor she was very happy to welcome this new baby, but on the other hand, she was scared she would lose the attention. She didn't want to describe further her work, but around the end of the session, she added.

"The baby will be healthy; I heard my mother say….I want to be like him."

With only one sentence Eleonor was opened a new window to her fear and insecurity. This child would give her parents less complications, and she would have liked to give the same to her parents, enjoy a healthy life style. When asked about her parents Eleonor mentioned:

"My mother is so beautiful, and my father does a lot of sport."

Because of the disease, Eleonor was pale and very thin. In her family, she was suffering the idea of being a perfect child as her parents would deserve. In Eleonor's imagination, her parents would want a child that is more similar to them. Finally, after this conversation, Eleonor described her situation.

"I don't like to eat….. I don't like to take the pills, they are very bitter…..When I come here at the hospital, I like to be invisible, and nobody sees me, I like to hide."

Eleonor, never mentioned these feelings to her parents because she tries to be as much similar as possible to them. Returning on her first drawing she mentioned:

"My legs are weak….. I don't like to walk a lot. ….. I haven't told that to my mother… not to the doctor…. My mother likes to walk, and I will walk with her."

At the end of the session, Eleonor started to bite her thumbnail again. She turned upside down the drawings, because she knew her mother would enter. Even though in the drawing there was nothing written she believed that her words would be showed somewhere around this images. Again she was looking puzzled at me, if I was going to talk long with her mother and we just explained that we draw two persons, and the color we used, and her mother felt proud that she chose the colors alone. Then she left the room walking slowly, holding her mother's hand.

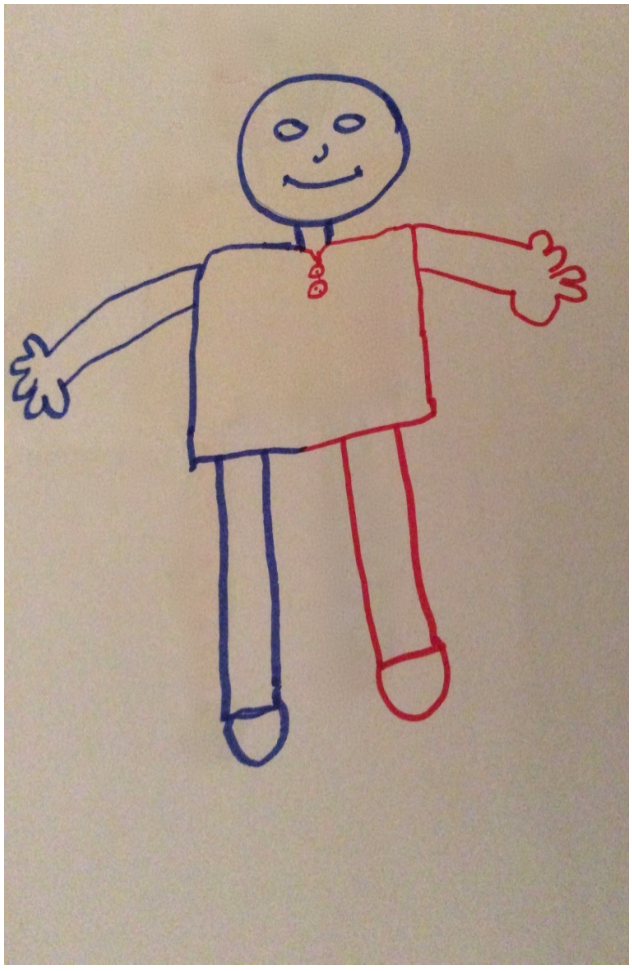

Figure 12: Second session, Eleonor 7 years old drawing a person

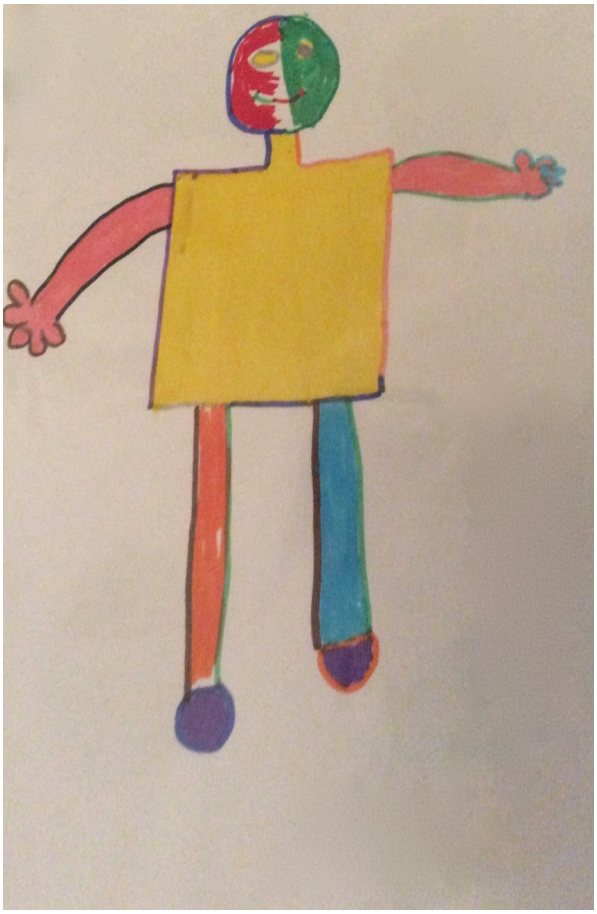

Figure 13. Second session, Eleonor drawing a person

Vanessa

Vanessa entered the room with her mother. This time Vanessa rushed to sit in the chair to avoid any contact between her mother and me. Her mother closed the door and left calmly with a serious face.

"You have no idea, my mother didn't leave me one minute alone."

The first minutes of the session Vanessa preferred to spend complaining about her mother and how difficult it is for her to be all the time surrounded my her mother. Then she took a deep breath and asked for the task of the session. She understood immediately the task and grabbed the white paper and colors to start the drawing.

"It's very easy for me this thing. I don't have to think. If I wake up without my disease, I would like to be 8 years old, and I want my name to be Lorena."

Vanessa, had very specific idea. It sounded that she has been thinking about this question many times before and now was just expressing it out loud. She told the story of one family she met at the church. They are very "emancipated" referring to Vanessa's words. They treat their children with respect. They ask their children if they want to do something. This description was completely different from the situation at her home and the relation with her parents. The family Vanessa met at the church, have a daughter of 8 years old and Vanessa imagined how would be to have a family where she can have a choice for her life.

She drew a smiling girl on the paper with green eyes and an orange dress. Vanessa's disease does not give her a lot of pain. Nonetheless, she can continue a normal life, despite the visits at the hospital for the regular treatment. Her primary concern was her family situation. At some point, her revolt would look as teenagers crave for independence, although, her case came more explicit after he description of the little girl called Lorena.

"We are Egyptian. We get married very early….. my mother follows me everywhere because she doesn't want me to like anybody (boy),

cause my family is planning to engage me with someone I don't know."

Vanessa's concern was very distinct. On the first session, she mentioned that she sympathizes a boy at the church, and this would completely cause a disapproval in her family. She rushed talking about her sister.

"My sister is just two years older than me, and she has one baby. I like her a lot because she can have a lot of dresses and things to wear, but I don't want to have a husband."

Vanessa envied Lorena for her freedom to choose her life. Finally, Vanessa became clearer to describe her situation. Differently, from all other cases, Vanessa was using the visits to the hospital as a chance to be free and to postpone her time to get engaged.

"When I am sick, they think to give me a few years till they engage me. Maybe I find a way to tell them about this boy I met at the church."

Vanessa continued discussing the dynamics in her family, till finally, she understood the time ran so fast and the time for her medication came, and her mother knocked on the door punctual. Vanessa left the room nervous to meet her mother, but gave a big smile when looking at the drawing of Lorena on the paper.

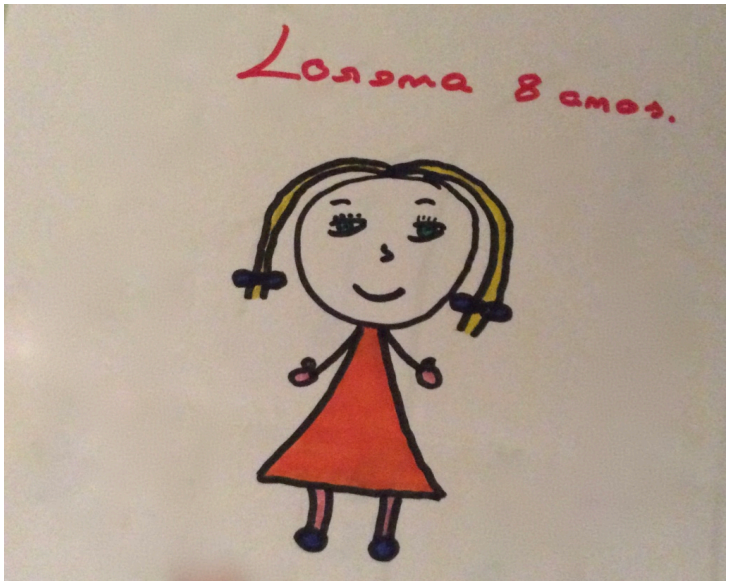

Figure 14. Second session, Vanessa 16 years old drawing a person without chronic disease

Session 3

In the third session the subject was "If the pain or chronic disease was a person/object what would it be?" This was a very interesting session opening new discussions and reveal the core of their problems. The sessions aimed to generate coping mechanism that would help each of the children cope better with the health condition in relation with the pain, hospital staff, and their life (family and social).

Patricia

Patricia came very happy on the third session and very motivated to draw. She didn't need the presence of her father to bring her into the room, she already knew where it was, and in a rush, she closed the door, sited on the chair. Patricia, was smiling, her eyes were shining and she couldn't hide the happiness. She responded immediately to my invitation to talk about this joy she was experiencing. She explained that it was her father's and they were going to celebrate it with the family. Patricia was wearing a short dress, a little worm for that day but she was very happy and couldn't wait for the day to end so that the dinner would come fast.

The session aimed to focus on her disease, her happy mood was a barrier to invite her and discuss about this delicate topic. On the other hand, the happiness would free her from the emotional burden and describe better her health condition. After introducing the task of the session, interestingly, Patricia didn't think a lot how to portrait the disease. This time she reached by herself the paper and the colors and without any word she started to draw. About 3 minutes after drawing she intervened:

> *"I am not finished yet…. I will make three girls in this paper."*

Patricia drew herself going to school with her friends. She putted herself at the end of her friends and with a tiny body, a little bit fat, also with a small face. To understand more her image she continued:

> *"It's like every day for me… my friends, they walk fast…. I can't walk with them… my legs are fat."*

At the end of the drawing, she putted a small bird flying in front of her friends. She explained that the bird, is very light and can go very fast in places. Patricia, felt a little bit sad after seeing her drawing but afterwards, she added:

> *"They don't know me… If I tell them my disease, they don't understand. ….."*

Patricia believes that her friends won't understand her disease and everybody may want to avoid her. She is attending her elementary school on the first grade. Patricia continuously blames her disease as the source of her problems. Then she follows introducing the girls in her drawing going to school in the morning.

Patricia- The first one is Joana, Maria, and the first one is Ana. She is very elegant. I like her.

R- And where are you?

Patricia- I am the last one. This little thing

R- You are very little in there

Patricia- They don't see me.

R- Why do you think they don't see you?

Patricia- They don't. I miss at school many times, and they do many things together.

R- What do they do together?

Patricia- They play with dolls, they draw, they run… I can't go with them

Patricia tried with her limited vocabulary to explain her lack of interaction with peers at school. She finished putting the last details on the paper and then looked at me, in a way asking not to talk about this anymore. It was already half of the session, and she was very fast drawing this time. After a while, I invited Patricia to talk about the dinner for her father's birthday. Her face shined again, and now she can't stop talking. She took about 10 minutes to tell all the details of the dinner, and all the people invited to the event.

Patricia added that when her father brings her to school she feels safer and she doesn't miss her friends. But this doesn't happen very often. Most of the time she goes with her brother. Returning to the drawing, Patricia added some more details:

> *"If Ana was sick…. Hmmm… she would be very bad… she doesn't know how to be sick…. Well, she doesn't know how to take the pills when the stomach aches, or when my eyes heart."*

Patricia became more optimist when thinking of someone else in the same conditions. She understood that after all these years she has improved a lot and learned how to deal daily with her pain and disease. Before ending the session, she was going to extend the legs of the last person on the drawing (her portrait) to show that she is bigger, but then the picture would become *"ugly, "* and she left it like that. There is just one attempt proving her idea, a long line coming out from her arms with gray.

At the end of the session, she remembered her father waiting for her and she became happy again. She just gave a smile and ran to meet her father, without asking to help arrange the colors or the papers. Patricia, shared many details of her disease but when recalling her father, she would forget everything and run happily toward him.

Figure 15. Third session, Patricia 7 years old drawing her perception of chronic disease

Ricardo

Ricardo came accompanied by his mother in the room. He had some health complications during the night and was feeling a little weak. He sat in his chair, and asked his mother to leave. He smiled at me, and putted his hand on the table showing he was ready to draw. After hearing about the task, he was confused with the idea of symbolizing the pain or disease with an object or person. He took a few minutes, got up from the chair and went to the room. Ricardo approached to the window and was looking at the stadium.

He stood quiet for a while staring at the stadium. This lasted a few minutes and then when he felt ready, he sat again near the chair and took the orange color.

"This time I am going to use just one color."

His hands were shaking at the beginning, and I rushed asking if he wanted more time, but he interrupted with a smile and started to draw. I didn't intervene till he finished drawing and at the end, he drew a person and wrote in the body of the person his name Ricardo. Added also the glasses in the head of the person to look more similar to himself.

"The disease is me…."

He threw the color on the table and was looking at the paper.

R- You draw a person with the name Ricardo

Ricardo- Yes, that's me

R- Do you like to tell me why you drew yourself?

Ricardo- Because I am the disease

R- Can you explain it to me?

Ricardo- hummmm…. I have been sick all the time; I don't know another way… so I am the disease.

R- And how is this disease?

Ricardo- It's boring, it's sad, it never stops.

Ricardo this time felt ready to express more that he would have imagined about his health condition. So he added:

"The doctors called my mother saying that the treatment was not helping me… they started to cry, and I don't know what to do…"

Ricardo has always been patient with his disease, but this time, he was insecure and scared mainly for his family. He felt that his disease was destroying the equilibrium in the family. Ricardo stood up again to reach the window and watch the stadium again.

R- Do you remember any moment when Sporting (football team) lost a match?

Ricardo- Yes, many times

R- How did you feel?

Ricardo- I felt sad.

R- How do you think the football players felt?

Ricardo- Upset, angry, I think.

R- Do they play again after one loss?

Ricardo- Yes, they play till they win

R- Exactly! When you met them at the stadium, were they happy?

Ricardo- Yes very happy.

R- They had many failure in their life till arriving so far

Ricardo- I know what do you want to tell me (smiling)

R- What are you thinking?

Ricardo- You want me to be like them, to try till I win.

Ricardo smiled and came to sit near the table. His face was calmer now and started to tell about a failure in a very important football match..

“This Ricardo here at the paper has to smile.”

In the end, he added a big happy smile in the drawing.

"You know how to make me smile again… I feel different."

Ricardo ended the session showing some more details about his health condition and the discussions with his parents, but now he was alleviated. When the session ended, he left the room and gave me a smile waving his hand, giving again a glance at the window catching the stadium from far and hugged his mother, waiting outside the door for him. She didn't want to leave him alone, today after the bad news they had. She felt very surprised looking at his smile and hugged him back happily to see his smile.

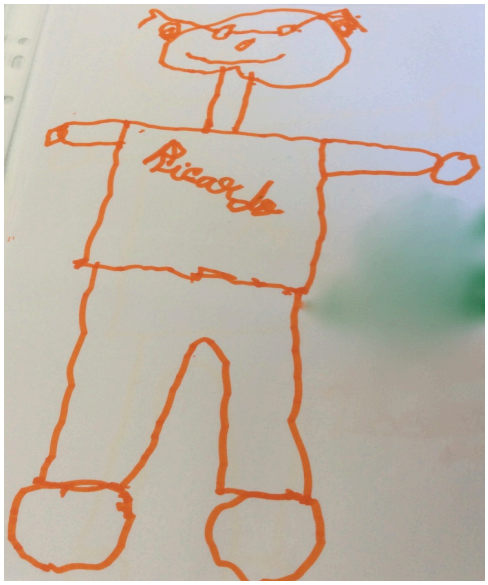

Figure 16. Third session, Ricardo 14 years old drawing his perception of chronic disease

Luis

Luis entered the room silent and sat in the chair. He avoided the eye contact and to my attempt to talk he avoided it immediately, grabbing one color and a paper and started to scribble around for a couple of minutes. I gave him the silence he wanted, and after a while, he broke the silence.

"I want to grow up very fast. I want to do things the way I want."

Luis stood in quiet for a while and then like magic he bit his words and started to look at me asking what to do for today. After explaining the task of the session, Luis gave a smile, like this task would know very well what he was thinking. He grabbed another paper and started to draw a person.

"This is my father. He is like my disease. They are both disappointing me."

Luis meets his father occasionally, and sometimes he doesn't come to the meeting, and that irritates him as Luis explained his situation as home later on. Before coming to this session, Luis had a phone call from his father saying that he can't make it to come for the weekend. His father had promised him to go for the weekend somewhere near the ocean, and he was waiting impatiently for the weekend to come. The plan got reversed, and Luis was irritated and disappointed.

Luis didn't like to talk much about his father and stood in silence finishing his drawing. Putted a lot of details and colors on the person he drew.

> *"My father lies all the time to me…. How is this similar to my disease? Well… the disease lies me also … I wake up feeling well in the morning, and afterward, I feel sick. I can never do anything cause suddenly I would feel sick".*

Luis spent the session talking more about his father and the poor relation he has with him. His mother was very indifferent to these episodes and most of the time she complaints in front of Luis about her ex-husband. Luis has ambivalent feelings toward his father, as he never knows exactly who he is. Sometimes he spends fantastic time together when they meet. He takes Luis in many interesting places that he has never seen before, but most of the time Luis is very disappointed cause he doesn’t show up to their meetings.

Luis putted yellow on the face of the person on the drawing. Based on the first session, yellow for him reflexes tiredness and fear.

> *"My father uses bad words, and gets angry very fast. Sometimes he throws things on the ground, and that scares me."*

Regarding his disease, at the moment he didn't know how to explain the parallelism but after a while immediately added:

> *"I am scared of my disease…. It doesn't hurt me so much. I am not afraid of pain…. I fear I am not the son my mother needs to help her. …… If I am sick, I can't work, I can't even play football to be a professional football player."*

Luis was all the time confused with his role in the family. He wants to become the provider and help her mother. Luis believes that the disease decreases the chances he has to be independent and provide for his mother. He putted a happy face representing his father adding that his father always smiles to him.

> *“The arms are unequal because when he throws things on the ground, his left arm looks so long that can reach many places.”*

Regarding his disease, Luis didn't want to explain. He just wanted to elaborate the revolt with his father. The feet of his father are green, and Luis mentioned that he is happy every time they go together, that's why he filled them with green shoes. Only at the end of the session he mentioned:

> *"When I play football I am happy. I can't run a lot, but when I play as a goalkeeper my hands are not strong, and I lose."*

On the drawing he also made very thin arms compared to the body. While he was drawing his father was imagining as well the moments he feels weak and how is the disease impeding him to perform things he likes. At the end of the session, Luis pushed away the drawing. He left the room, no smile in his face could be detected, but was calmer than the beginning of the session. Luis rarely discusses about his father to his mother, reason why his irritation from the beginning of the session was an accumulation of an extended period.

Figure 17. Third session, Luis 12 years old drawing his perception of chronic disease

Alex

Alex entered the room with his headphones but not playing any music. He gave a smile and sat down in his chair as the other times. Also, he asked if he could play a song and now he already knew some steps to dance. After having my approval, he unplugged the headphone and started to play the music. He knew by heart the text of the song, even though the song was compound from a few verses and repeating them continuously. After hearing the music, he opened the space around to dance. We pushed a little the table from the middle and created enough space to dance. He first performed a few steps to show me how to follow without the music and then with the music he taught me very kindly the steps to follow.

His eyes were so bright at the moment he was dancing. During this time, Alex had some breathing shortness. He could not move and speak at the same time. We agreed I would follow his steps without his intervention. He felt so happy and finally laughed when we were making some mistakes. Alex has always been very serious and looking at him laughing and enjoying the moment was very important. When we finished, Alex without my request putted order again in the room, taking the table in the middle of the room and this time sitting next to me.

The entrance of dancing took around 15 minutes. He knew that the remaining of the time was shorter than the other times. After explaining to Alex the task he immediately gave a smile and took the paper. He didn't want to put any color but just a pencil and the paper drawing a tree.

> *"I like trees, they grow up high. But I like them more when they are green, not without the leaves."*

The tree he prepared was made only with a pencil in wintertime, with no leaves and fruits.

> *“My pain is like this tree. I try to get old and become myself, learn new things, have friends, go out, but when I feel the pain, I have to stay at home. I can’t meet my friends. I can’t play. Just stay inside imagining how my friends are having fun. ……...The leaves are like that….. I can do only a few things I like, the others almost don’t exist”.*

Alex got back into his grumpy mood and started to scribble on the paper.

R- Do you like trees?

Alex- Yes

R- What would you do to this tree to come back to life? What does the tree need?

Alex- I would water it very often

R- Yes! What else?

Alex- I would work the ground so that the tree doesn't take any wombs

R- Would you talk to the tree?

Alex- Why? No!

R- Gardeners say that if you talk kindly to flowers and trees they can grow faster.

Alex- Really?

R- Would you talk to the tree to have this result?

Alex- Yes… yes of course.

R- What would you say to the tree?

Alex- Hum… I would say, that I am here, and if the tree needs me, I will water it all the time and protect it.

R- How would you protect it?

Alex- Watering.

R- Who would you protect the tree from?

Alex- From the ground and the cold.

R- Can you do that?

Alex- Well when is winter I can't

R- So there is one moment that the tree has to follow its fate, but then in spring it recovers again, brings more flowers and leaves

Alex- Yes many.

R- If the tree was like your pain, do you think you can also treat your pain the same way?

Alex- How, I can't do anything to that.

R- You are already doing. You are taking the medication, and coming at the hospital. It's the same as the trees, when you water it.

Alex- Yes, I guess, I am doing it

R- But we learned a new thing, we can talk to the tree, so you can talk about your pain, how you feel. That is the way to be heard. Do you think you can do it?

Alex- Who I can talk to?

R- You started to talk to me. Was it hard?

Alex- No

R- I think it will be the same if you talk to your nurse, or your mother. Who do you feel more comfortable to talk to?

Alex- My nurse. She hugs me when I come here

R- Next time you will see that the same as the tree, you will feel better

Alex for a while stayed in silence and was looking empty in the direction of the window. The silence continued for a couple of minutes, and he immediately broke it by proposing a new drawing. This time he chose a small paper on the table and started to draw with the pencil. It was a big boat floating in the ocean.

> *"I am in the back of the boat…. Is going somewhere very far. The ocean is very peaceful. I am happy I am on the boat. No… I am not running away; I just like to be on my own."*

The last drawing of Alex contained the same image the text of the song he played at the beginning of the session. Details of his songs surrounded his imagination. At the end of the session, we discussed the song for the next session, and his face brightened again. He left the room with shining eyes. Before leaving, Alex helped me to arrange the room and then said goodbye.

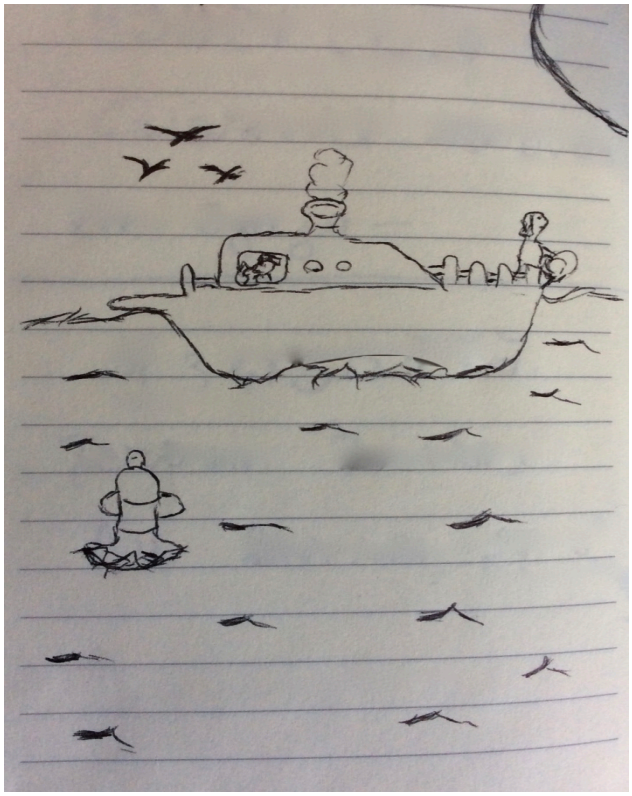

Figure 18. Third session, Alex drawing his perception of chronic disease

Figure 19: Third session, Alex 12 years old drawing his perception of pain

Eleonor

Eleonor entered the room holding her mother's hand. They both entered and sat next to each other. During these weeks Eleonor didn't feel very well, and they had to anticipate the visit at the hospital. Eleonor was pale but more comfortable in the room. When asked her mother to leave, she didn't give any signal, just started to bite her thumbnail and looked at her till the door was closed.

In the beginning, Eleonor didn't needed me to repeat several times the task of the session, so we had to divide the task into small parts for Eleonor to understand. It took a few minutes till Eleonor could understand and also to break her silence. All questions she replies with a smile and movements of her head.

I took a paper and invited her to draw. The colors were all next to the paper, and she had to choose. She chose the blue color and scribbled on the paper but no shape. Despite my attempts to invite her to draw something that would come to her mind she just replied with a shy smile. I took my notebook and started to draw something. She was curious to see, and I invited her to join. I gave her my notebook, and she grabbed my pencil and opened a new page drawing something hidden from my sight.

After finishing she putted the notebook on the table and looked at me for any reaction. In the drawing, she created a girl very similar to herself wearing a dress, long hair and very thin, but short (figure 19).

> *"…Her name is Constança…. She has beautiful hair,… No, she doesn't have any color, because ….. when I imagine her …. I don't imagine her with colors."*

Eleonor drew the image of a girl with the name Constança that represents her disease. The girl on the drawing is not any of her friends, or someone she knows. Eleonor added that in a movie she liked this name. The connection of this girl with her chronic disease was not clear at once as Eleonor has difficulties describe her thoughts in continuity.

R- Eleonor, I like your drawing is very beautiful

Eleonor- Thank you (brushes)

R- You said that you like the hair of Constança. How are they?

Eleonor- They are long, and ….. blond

R- What else do you like in Constança.

Eleonor- ….. Just the hair

R- Is there something you don't like?

Eleonor- (smiling) Maybe…. She doesn't talk

……

Eleonor- Constança doesn't play. She doesn't listen, …. She is angry. she is alone

R- Who is she angry with?

Eleonor- Everybody

R- Can you talk to her?

Eleonor- Yes… sometimes

R- You seem to know very well Constança

Eleonor- Yes… she talks to me

R- Do you help her?

Eleonor- Yes (shyly smiling)

R- What do you do to help her?

Eleonor- I listen to her.

R- Does it help Constança?

Eleonor- Yes, she talks to me

R- What else do you do?

Eleonor- I am her friend. I understand her

R- What do you understand?

Eleonor- Why she doesn't have a friend.

R- Does Constança help you?

Eleonor- Not a lot, but she is my friend too

…….

R- Constança feels better when she talks to you. Do you have someone to talk to like Constança does?

Eleonor- No….

R- You listen to Constança, and you understand her. Do you think there is someone that can listen and understand you?

Eleonor- Yes…. My mother

R- Do you think if you talk to her, you will feel better like Constança?

Eleonor- Maybe

R- Do you think you will not feel alone like Constança?

Eleonor- Yes (smiling)

Eleonor didn't like to put any color, nor to draw on a big paper. She preferred the first drawing and was starring at it all the time. Our conversation took all the time of the session she needed to formulate her thoughts into words. In the end, she completely forgot the time but differently this time she didn't feel the urge to run at the door and meet her mother. When I confirmed the end of the session she took more time to help me arrange the table and then with a smile, but not bitting her thumbnail, she opened the door and hugged her mother.

Figure 20. Third session, Eleonor 9 years old drawing her perception of chronic disease

Vanessa

Vanessa entered the room without her mother waiting outside. She rushed inside and sat onn her chair. Vanessa was bright and happy. She spent the weekend at her sister's house, and she was feeling independent there, without her mother. She had a joyful weekend because her sister gave her many new clothes to wear. She envies the situation of her sister, her freedom to go shopping and have many clothes.

> *"I walked in the street alone, went to buy alone at the supermarket… it felt good."*

Vanessa understood immediately the task of the session and rushed with her colors on the paper. She drew a flying hand and some small clouds on the sky. The hand was open, and the thumb was similar to the head of a bird that would carry the body of the bird. The idea was very simple, her disease was like a hand.

> *"We have five fingers, they are alone but still attached to the hand. I like to think the disease as a hand, that has many moments, sometimes I am sick, sometimes I am tired, sometimes I am scared, and sometimes I am happy."*

Vanessa described her disease more as a good thing happening in her life, helping her in many aspects, such as gaining independence.

> *"When I was with my sister I understood that she has many things but she got married so early, and now with one child, she doesn't do what she wants to do."*

…..

> *“Maybe, you don’t know, but in our culture, the parents marry their daughters when they are very young. I am happy I am sick because they are not thinking to marry me.”*

Vanessa was not happy to be sick but was a ‘hand’ helping her not to accomplish her destiny, as her culture would want her. She is 16 years old and self-aware of her bad results at school. She confessed not being good at school and learning, but she would like to have a profession. She still didn't know what her ideal profession was, but every day was exploring more.

R- Your hand in this drawing is very elegant and beautiful.

Vanessa- Yes, if it were on the other side I would decorate the nails

R- Every time you come here, I see how beautifully you paint your nails.

Vanessa- Yes, I never get tired doing this.

R- You put a hand in the drawing. You said that the fingers could be independent, but still they are part of the hand. The same as you being part of your family.

Vanessa- Yes I know.

R- When we use the hand, one only finger can't do anything, but when they work together they do amazing things. They can decorate so beautifully your nails.

Vanessa- Yes, it's true. I always liked to do the nails. I can take some classes of it.

R- I am sure, to achieve a goal, you also can fly as the hand does.

Vanessa started to look her drawing differently, and after that, she added some flowers around the paper. Differently, from all the cases, the disease for Vanessa had a different purpose especially because her pain level is very low and her visits at the hospital are rare. Her culture, being Egyptian, would require her to get married from early ages, but coming at the hospital she met nurses and educators with a different perspective on life, and she understood the difference. Vanessa was starting little by little to comprehend what to do with her life but as well to accept her family and culture as part of her being.

At the end Vanessa looked at the drawing and gave a smile, added:

> *"I am happy when I am with my family… better than when I am in the church."*

She opened the door and smiled at her mother signing to go for the treatment. They both said goodbye and left.

Figure 21. Third session, Vanessa 16 years old drawing her perception of chronic disease

Session 4

On the fours, the session was the "Catastrophizing" the children had to link the elements of two tables, one describing their hospital experiences and the other their coping strategies. This session helps the children come closer to their coping mechanism selected while dealing with the hospital events.

Patricia

Patricia entered in the room sleepy. She had to wake up very early for a visit at the hospital. She came as usual with her father and brother. Her father was playing a game with her brother on the phone, and when Patricia came to the room he didn't check her out, and she felt disappointed, following with her eyes till she could not see him anymore, hoping he could wave at her.

She sat on the chair and opened her mouth. To my question about her father's birthday, she immediately replied happily and completely awake.

“We had so much fun… My cousins were there. We ate good things.”

Her eyes brightened when talking about the moments she spent with her father, and the way he hugged her. Patricia was happy, and that mood brought her beautiful memories also happy feelings. After explaining to Patricia the task of the session, she was looking closer to the list of the hospital experiences, and she agreed she had to go almost over all of them.

Patricia selected injections and blood drawing as two hospital experiences she prefers to be in the presence of her father, holding his hand. The connection Patricia has with her father is very important for her to generate positive coping strategies. In the case of hospitalization, she dislikes herself. This reaction is mainly related to the fact that she will be absent at school.

"I don't like when I miss at school, because every day they learn something new, and I don't understand anything."

Through further discussions, Patricia showed that mainly it's not the classes itself but her friends. She feels that when she is hospitalized, they avoid her at school and she has more difficulties getting involved.

"I was hospitalized three months ago…. I was scared… I don't like to be in bed."

Patricia's parents never discussed with her the health conditions, the reason why she is always puzzled when the treatment is going to finish. Patricia believes that in a future she will be cured and will not have to be careful about her health anymore. Patricia's strong relationship with her father, gives her trust to ask for information or use his "hand" support to talk to the nurse, so that she could listen to her health story.

"I wished I didn't have a problem… but yes… I can't be Ana (name mentioned in the second and third sessions) cause I know better what to do when I am sick."

Patricia talked longer about her feelings as continuing thinking about the same problem over and over again, and after many parallelisms, with Ana, she knows that gathering information will help her understand better and cope with the disease.

"Well… when I know how long I will be at the hospital, I can think what to do tomorrow. When I talk to you it's easier, you tell me everything but my father, he…. doesn't say. …. I will ask him, as I ask you!"

Patricia left the room with shining eyes and jumped out of the chair to reach the door and go to meet her father.

Ricardo

Ricardo was happier from the last session. He sat down and immediately rushed to say that his favorite singer will have a concert soon in Lisbon and he was thrilled because his father bought him tickets to go and see him live. He added that this concert could be a big one and he knew all the songs by heart.

Ricardo has very strong connection with his family, and they are very careful to his needs. He is comfortable, but at the same time, feels not equal as his brother that is healthy, and his parent can be proud of.

"My father bought three tickets. One for me, one for my brother, and one for himself. My brother doesn't like David Carrera, but he will come with us."

His hands were trembling more than usual, and he explained because of a new medication he is having giving him this side effect. Luckily the new treatment was having good results as well, and he was feeling better. This time no drawing, and he felt happy because couldn't draw anything. After seeing both lists, Ricardo smiled and remembered the conversation in the last session, about the strong relation he has with his family.

"I thought when I went home, and I saw my father is ready to do anything for me, my mother as well. So I decided I will be very close to them."

Again he referred to the lists and asked if I could help joining them with a line. The most exciting moments regarded the hospitalization and his feeling of angry toward it, and when he is tired on his legs, he usually blames himself.

"I very often come to the hospital to spend the night, because sometimes the medication give unexpected reaction and they have to control me during the night. I don't like that, because I can take care of myself as well."

Ricardo- It's been so many times I came at the hospital.

R- Do you feel sick when you come at the hospital?

Ricardo- Yes, sometimes I vomit, or I lose the equilibrium

R- And when you come at the hospital how do you feel?

Ricardo- hummm…. I know why you are asking me this… I feel better because they give me medication.

R- Why do you think I asked you?

Ricardo- To let me know that the hospital helps me better than at home.

R- I was curious to know if the hospital helps you feel better, faster than home

Ricardo- Well… yes, of course, it's faster. They have the medications, but I have to stay at the hospital

R- And at home it may take days to recover.

Ricardo- yes, maybe. Once I stayed home, and it took three days.

Me- So if you were at home, you would have lost the chance to see the concert of David Carrera.

Ricardo- Yes (smiling)

R- and you would stay longer in bed. And to this option from the list, you said you don't like yourself.

Ricardo- Yes, I don't like, because the more I stay in bed, the more I feel sick.

R- So, going at the hospital, in fact, helps you feel better and catch the concert of your favorite singer, help your parents knowing you are doing better, and you face the problem easier.

Ricardo- Yes, …. It's true!

Ricardo had many confusions in his head because of his health condition, but he never doubted the support of his family and this gave him a lot of courage to see various difficult situations differently. He continued to analyze his other replies and continuously was changing them, offering a different perception to the problem, always considering his parents as the bridge to achieve the goal.

Ricardo at the end of the session, despite his trembling hands, stood up to the window to see the stadium again and daydreaming about the chance to run and play football. His mother entered the room to pick him up, as he was feeling weaker. He smiled and kept looking from the window.

Luis

Luis had a discussion with his mother, and he entered in a room angry. He didn't say 'hello' but sat on his chair and took a paper scribbling around with a blue color. To my request to share his troubles, he replied with a simple move of his head, and lack of interest discussing at the moment. He continued scribbling on the paper for a few minutes then added:

"One day I will be old to decide what to do!"

The situation remained unknown as Luis didn't like to share his thoughts, and he stayed quiet. I waited patiently, till he decided to talk himself about the situation. Then I introduced the task and Luis without whispering using the same color holding in his hand started to link the elements of the two lists.

Luis lately has been having a lot of pain in his shoulder and legs, and this worries him, also makes him overthink. He has a strong motivation to succeed in life and be able to support his mother. Furthermore, Luis believes that his

father doesn't come very often to visit him, because he needs special attention, and his father is not able to give.

R- Luis you selected “I continue thinking for a long time” when you have pain.

Luis- Yes

R- What do you think?

Luis- I think my pain.

R- How is your pain?

Luis- Continues for long, and scares me

R- What scares you?

Luis- Well …. It scares me that I can’t make it stop.

R- When you have the pain, do you ask for help to your mother?

Luis- She is outside most of the time

R- Do you talk to anybody about your pain?

Luis- my grandmother sometimes

R- And how does she help?

Luis- She just gives me a medication, but that doesn’t stop the pain.

R- Does continuing to think about pain, help?

Luis- (smiles) No

R- If you were grown up, what would you do?

Luis- I don't know……I would come to the hospital and ask the doctor.

R- So you would find solutions?

Luis- Yes of course, because I will be grown up.

R- Do you think that if you ask for help to the doctor now, they will not reply to you?

Luis- No they will reply

R- So actually, you don't need to think when you grow up because even now you can find new solutions.

Luis- Well, if I am at home, I can’s ask the doctor.

R- Do you think you can ask today? So that when you have pain again you know what to do

Luis- (indifferently replying) I think.

Luis lives with his imagination in the future wishing he was old enough to be independent and forgetting to find the solution to the present, and as a result, no matter how much time passes, he still think is not old enough to ask for help.

Continuously, Luis discussed his daydreaming feelings when having an injection. He always dreams to be a football player, although this goal is more related to a wish to earn money in a faster way and help his mother. This big dream to be a football player is very important to imagine his life as well as a fighter in a match, and never let go despite the difficulties.

Luis prefers to be alone when is at home. He loves his mother, but she is not very present at home because of the work, and this makes him believe that he is the reason why she is putting herself into long hours of job.

Luis took another paper to scribble around and then when the session ended, he was lazy to leave the room, postponing the time to go and have his treatment. But his nurse knocked on the door, waiting for him and he lazy stood up. With a nod said goodbye and left the room.

Alex

Alex came happy in the room with a big smile, and his headphones were not playing music. He said hello and rushed to sit in the chair. This week he has been to the club where his mother works and has danced at the club. He was happy, especially because he didn't know he could move his legs correctly until other dancers at the club were complimenting him.

He wanted to play another song he has learned how to dance these days and was waiting to show me. The first minutes run fast as Alex performed as well his steps he learned at the club.

"They all liked my dance…. My mom was very proud. You had to see when she was saying, 'that is my son'."

About the task of the session, Alex was very collaborative and happy to talk about his hospital experiences. Once again he shared that he is still angry when he is tired from his legs, and this doesn't allow him to perform and rehearse the steps he learned. But this time his anger was more as a moment reaction because afterward he said that I find a solution, and we both discussed the option to pause the dancing for a few minutes, and take deep breaths, till his feet would feel better to dance again. He agreed immediately, as long as would profit to rehearse the steps for the dance.

Till the next session he promised to perform this strategy and even if something else would encounter, he would always try to find a solution. Alex, was ready for this judgment from the other session when we discussed his tree, and the need always to find a way to deal with the situation.

As regarding the situation when he meets the doctor he replied that he doesn't want to listen and avoid any contact.

Alex- They always say the same things.

R- What do you want to hear different?

Alex- I don't know… but I don't understand them

R- You are saying that they use words you don't understand?

Alex- Yes

R- You also mentioned you don't listen. Do you think, you don't understand the phrase because you don't listen to all of them.

Alex- I don't know…

R- Maybe the doctor also mentioned some strategies how to feel less tired on your legs, and you can dance longer.

Alex- I don't think he mentioned

R- But if you ask, he can suggest some strategies. Remember the Tree from the other session?

Alex- Yes I do…

R- If we don't know what the tree wants, we can't help her recovery. We can water her, but maybe she needs the sun.

Alex- Yes, the flowers need a lot of suns

R- Like you need to dance

Alex- (smiling)

Alex left the room thinking of the next song to sing and prepare for the other session. His connection with the music was very deep and helped him also connect better with his mother. The changes in Alex behavior were very obvious. For the first time he was trusting to talk to one person and for the sake of dancing he is accepting to be more open with the doctors and the hospital staff.

Eleonor

Eleonor differently from the previous three sessions, entered alone in the room. Her father was waiting outside, and she came biting her thumbnail. Her father took her hand off her when the door opened, and she didn't react. Eleonor came closer and sat on the chair quietly. To my question how was her weekend she replied with a simple nod. Latter she added that her mother is at the hospital waiting for the baby to come. She arrived at the hospital with her father today, and now the house is getting ready to welcome the new baby.

In this session Eleonor described is feeling a little neglected, especially because all the attention goes to the things the child will want and everybody asks about him already. This session is going to be a little bit difficult for Eleonor, as there is no drawing but a task that requires conversation and she is very shy to open. After introducing the task to Eleonor, she grabbed a pencil and started to read the lists. She didn't like to discuss while working. She was very attentive on every word, reading them twice, and sometimes erasing with a rubber some replies. The process for her was long and took the necessary time she needed to finish.

Interestingly, Eleonor for the ‘medication’ experience selected as a coping strategy ‘talking to a friend/family’.

"I remember when you said about Constança, and I've spoken to my mother. I don't like the taste they have, and she chose to give me different pills."

Despite the fact that Eleonor is very shy, she continues to enter deeper in the conversation we have. She started to make a change (talking to her mother about the medication she is taking) and saw the results of this approach immediately. She found the person she trusts more and as a results opened a new window to deal with the health situation. Also, this result, made her trust the session and enter alone without holding the hand of her father.

Although, Eleonor says that she blames herself when she has a high fever. This is mainly related to the moments when her mother was pregnant. Her mother had to take care of her, and sometimes she would feel sick too.

"The baby might get sick too when I get sick."

Eleonor's reaction was more related to a particular situation, and she adds:

"I will try not to get sick, cause I want to help my mother, and I can go and kiss the baby."

Eleonor was becoming opened to talk and also the results from the lists were impressive, very different from the first questionnaire she filled before the sessions. Improvements were also seen in the way she sits in the chair. Before she used to sit only on the border of the chair and now she sits comfortably on it. She is still very undecided about the colors to use, but this is mainly related to her will to have a perfect combination. As well, Eleonor, likes to take her time to think, she doesn't like pressure, and when you give her the necessary time, she interacts without difficulties.

The session continued with the other elements of the list and Eleonor, now believes that her mother can be a strong alliance to help her feel better. Differently, form her replies in the questionnaire, she never selected family or friends to be a trusted person to talk when having a difficult situation.

Vanessa

Vanessa was happy for this session. She entered and happily showed me a small paper. She has talked to the church and they have discussed with her

family to help Vanessa enroll in training to become a hairdresser. Her family didn't accept at the beginning, but Vanessa waited patiently till they approved her choice.

> *"I did it… I don't know how I got that courage to face my father but I talked to the pastor in the church, and they told me that many friends would contribute to paying her first month of course. ….. when I spoke to you I realized what to do."*

Vanessa was very happy with this solution and more importantly, she now can be more independent and very soon start a job that she liked to do. This mood helped her find a better solution to her situation and now was a moment to focus on her health condition. When introducing the lists, she chose for most of them to talk to friends, find solutions, think positively, etc. Although in two moments Vanessa preferred to be alone and watch television when she has to stay in bed for a long time.

She explained that staying in bed was mainly related to her menstruation pain and sometimes also the headache. She again introduced her culture saying that for the women are not allowed to complain about these type of problems. In many cases, she has been alone in her room waiting for the pain to go away and then go out. Once again, the reaction is more related to a specific situation and the cultural aspects. Although after discussions, Vanessa understood that after talking to her doctor she could prescribe her medication even for this type of pain.

Vanessa was discovering very little things, but that would increase her wellbeing. She was confident to be independent and learn how to achieve her goals also involving her family. Regarding the moment when she has a headache, she likes to dream how she wished her life to be. In many cases, the goals involve the friend she met at the church. As a teenager, she is enjoying the approach with the boy at the church. She confessed that the Pastor is all the time around and his presence makes her confident to trust this new friend. Also, her mother gives her more space when the Pastor is around.

After a lot of discussion with Vanessa, the session ended very fast. This happiness gave the courage to deal with any problem she would handle, and for

the moment in her situation, it was to escape the fate of her culture from getting engaged, at an early age. Vanessa left the room with a big smile and opened the door where her mother was waiting.

Session 5

The fifth session invites children to build a pyramid of needs. By drawing a pyramid and dividing it into five levels, they can classify activities they want to attend, but their health condition constrains them. In continuity, children are encouraged to describe their feelings and generate some alternatives to these limited activities.

Patricia

Patricia in the morning was in pain and vomiting, nurses rushed to give her medications and brought her to a room to relax. While she was in the room with her father and her brother she was feeling better. Her father and brother were playing a game on the phone and Patricia felt neglected. When I entered the room, her face brightened and then looked at the serum on her arm noticing me that she couldn't come to draw today.

We had to postpone the session for her next visit at the hospital. She started to cry when hearing the news, but then the nurses due to the situation gave her a very proximate time to come again at the hospital, in 15 days. Together we counted the days and agreed that there was going to be just two weekends and she was going to come again to the room to draw.

On the session after 15 days, Patricia entered running and sat on her chair looking at me with a smile on her face. When drawing during the session, Patricia learned as well to control the distance between her eyes and the paper and also to hold less tight the pencil on her hand.

> *"I can write faster now, and my glasses don't fall. My teacher showed my homework to the class…. Because I did an excellent homework."*

Patricia felt proud of this improvement because from that moment, her friends at the class started to talk more to her and for one week she has been going to school with her friends holding hands. Her father continues to take her to school every morning, but now that she has made friends, she was not focusing her

attention on his presence but was impatient telling everything she has done with her friends.

> *"They asked me if I would like to go to the Irena's house, to have a snack together…. I said yes. I am going tomorrow after school. My father will not come to pick me up, Irena's mother will pick us up from school and then my father will come to Irena's house to take me."*

Patricia took the first minutes of the session describing her friends and their discussions. She was very pleased with these results and was illustrating in details the conversations with her friends at school. The subject of the session seemed to have a perfect aim for the situation Patricia was going through.

Patricia drew a pyramid, then we divided it into five levels, and Patricia wrote the activities she likes more to do such as go to the beach, go to the park, play, swim, and draw. She randomly mentioned a few activities she likes to attend. On the peak of the pyramid, she mentioned, "go to the beach or swimming pool." Coming from the summer, Patricia still has nostalgia for those days when she went to the beach with the hospital group.

> *"I like to go to the beach, it is very beautiful, I like to swim."*

Patricia still had insecurities about her body and her friends. She didn't know whether this friendship she created would continue. She wrote as well "play" and added by saying that she wants to play with friends. Patricia is concern that her friends will leave her aside when they recognize her fat legs. After a while she also explained the real reason. Patricia feared that if her friends knew about her disease, they would leave her. Furthermore, she doesn't trust herself to be able to keep for a long time being popular and having friends.

> *"If they see my fat leg they will stop being my friends….. what if they know that I am sick…. Well, I am not sick, but I come to the hospital…. They can get scared….. No… I am not frightened of my disease…. Well because I know what do I have. …. Maybe if I tell them I show them that is not dangerous."*

Patricia fears that her appearance, as well as her health conditions, will jeopardize the connection she has with her friends. And losing her friends is the

worst situation she can think of. Now she is trying very hard to be with them and sometimes even please them so that they agree to go to school together. Patricia is very insecure in her abilities to have a friend. Then the rest of the session we improvised many situations Patricia feels insecure with her friends.

At the end of the session Patricia described some of the moments, she feared to lose her friends, and we improvised some situations to prepare her when facing these difficulties.

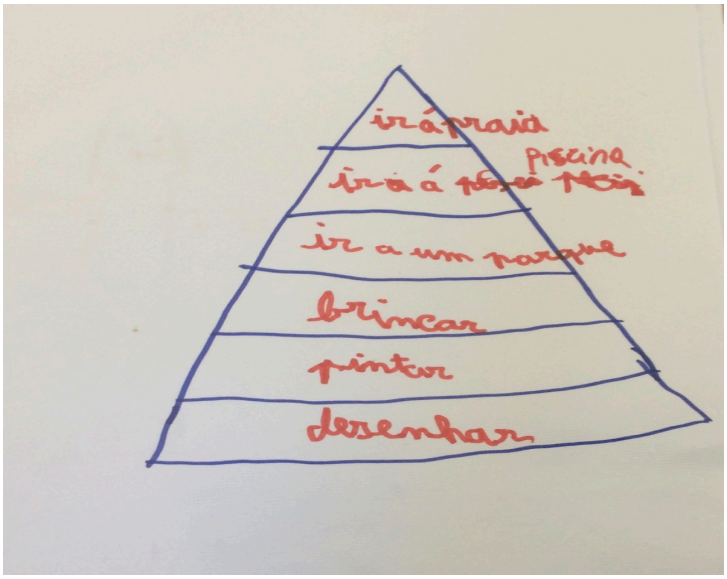

Figure 22. Fifth session, Patricia 7 years old drawing the pyramid of needs

Ricardo

Ricardo was feeling much better this time and so happy. He had his birthday a few days ago, and on the table, there was a card wishing him happy birthday. When he saw the card, he felt so happy and gave me a hug. He sat, and his eyes started to tear. He said that this was his best birthday ever. His father took him at the stadium to watch the concert of David Carrera. He knew all the songs by heart, and they were very close to hear his voice.

Ricardo mentioned the next day losing his voice, cause all that night he sang all his favorite songs and this was his perfect celebration. At the same time, he felt very tired and weak but held close to the images from the concert. He described

in details the concert, also showing some pictures his father took from the mobile.

His hands were not trembling as much as the other time. When he heard about the session's subject, he took the paper and the green color and started to create a pyramid. He divided the pyramid into five levels as well and began to write on them. His writing was difficult as his hand was trembling and also he would hold very tight the pencil. The writing is very difficult to understand, but as usual with his patience, Ricardo explained everything. He started from the low level writing ‘swimming' then continued with physical activities, afterward, learn at school, and finally play football and run. On the peak of the pyramid, he didn't put anything, as the football had to be his major wish.

For the entire session Ricardo discussed his very few possibilities to run and play football because of his health condition but from the fifth session he mentioned:

> *"…but I think ‘Sporting' doesn't quit when they lose, so I have to try again."*

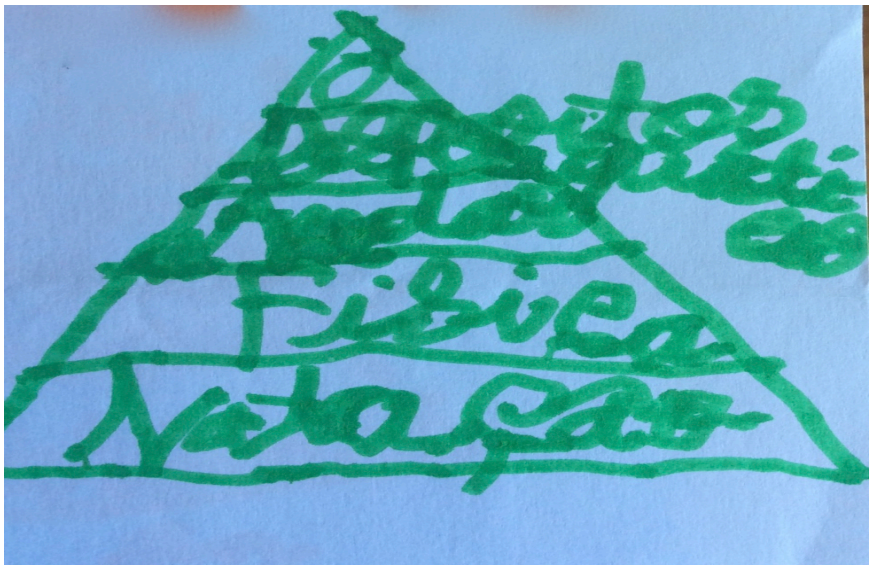

Figure 23. Fifth session, Ricardo 14 years old drawing his pyramid of needs

His message was very deep and felt, especially because lately Ricardo has resigned with his disease and accepted his conditions. He discussed about all the times he was feeling left aside at school during the physical activities. He

has some friends. His best friend is called Franco, and they used to spend a lot of time together. Unfortunately, Franco left the town and now lives in another city with his family. They meet very rarely, but he misses his best friend around the neighborhood.

Luis

Luis was calmer this time when entering the room. He seemed to have resolved that discussion with his mother. However, he liked to be quiet and not talk for the first minutes, just getting lost in his eyes from the window. Eventually, he looked at me to show his readiness for the session.

Luis took the paper and the red color and created a pyramid. He wrote on the top Football and then continued with Music, then swimming, and finally be rich. No surprise on Luis's choices as he has mentioned all the time his wishes and his needs. The focus of this session mainly directed on his need to play football and as a result to be rich very soon.

Luis was impatient to be grown up. Although, he mentioned that he asked the nurse about his pain she suggested a few medications and messaging that would help him. Luis has been for all this time using these recommendations, and the results have been good he mentions.

> *"I do massage my legs before going to play football, and I feel less tired. Also during the game, I take some pauses to relax my muscles."*

The discussion then focused on the football players. He mentioned his favorite football players and also some of the reasons he liked them.

> *"I like Ronaldo, yes he came from a poor family as well and now he is so famous. ….. Yes, of course, he had difficulties arriving till here… but football is not easy to play. You have to get tired a lot."*

Luis continued discussing his ideas on how to become a football player and the fact that the massage was giving results he was feeling happier and confident. He was having hopes again that soon he can start play football as a professional. Hope is very important to keep track on what you want, although,

as long as the hope doesn't exceed the possibilities, it can help your motivation. Luis was dreaming far, for the stage he was. And we had to cut the problem in pieces to see what are the chances to be a very famous football player. At the end of the session, the discussion discouraged a little bit Luis, but he was very motivated to try hard and achieve his goal.

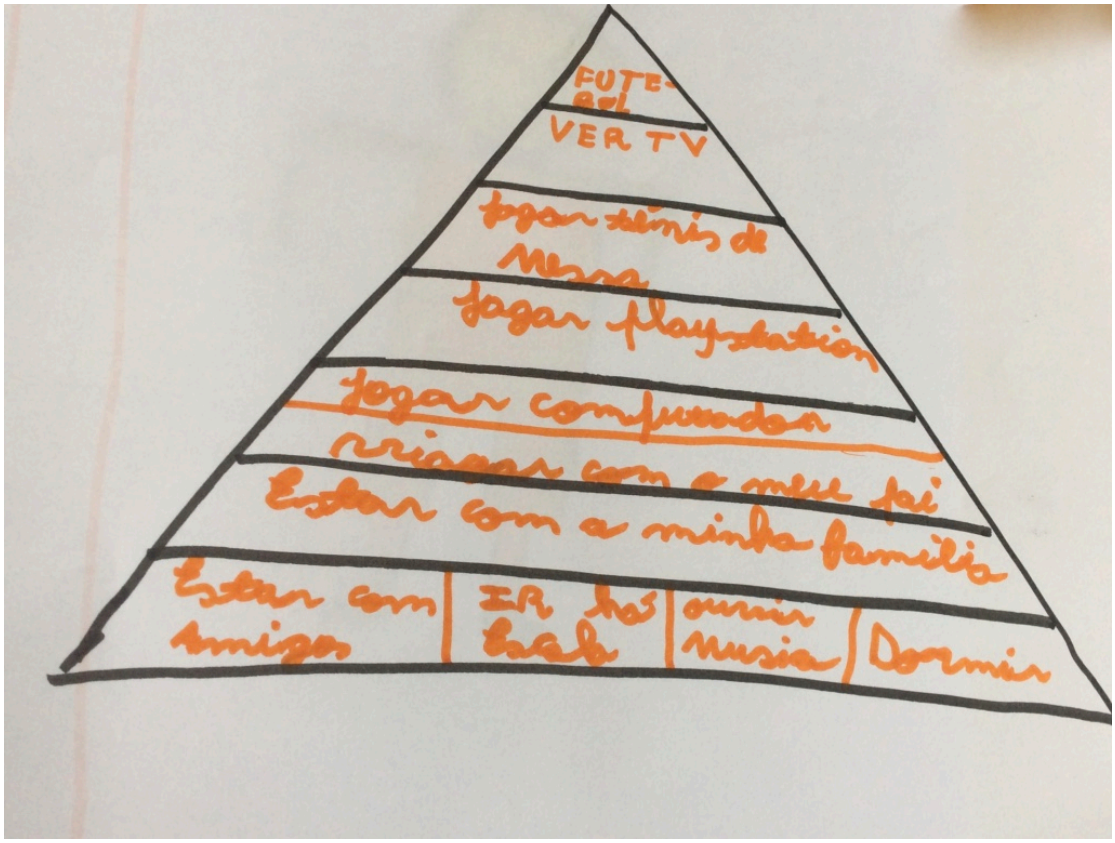

Figure 24. Fifth session, Luis 12 years old drawing his pyramid of needs

Alex

Alex, as usual, came with his music and started to play a new song. He learned new steps and was feeling prouder of himself. He showed the steps and explained to me the song. After that, he mentioned that African music is even more impressive. And his wish is to start with Reggae and then learn the African dances.

When he heard the task he felt relieved, he knew precisely what to put on his pyramid. So he drew it and divided it into five levels. He started from the low level, but to him the most important, writing Dance African songs.

"I think I can also sing African songs. My mother says that I don't have a good voice to sing."

Alex from the first session has .

“I don’t like football so much, but I can play with my friends. But I know I can sing an African song.”

He has started to trust himself, and believe in his abilities. He has a motivation now, and he had compliments about his dancing passes. Alex's eyes were sparkling when talking about the dance. He understood the subject of this session and started to talk longer about his dancing technique. To him, dancing was not an impossible task, but now he had hopes.

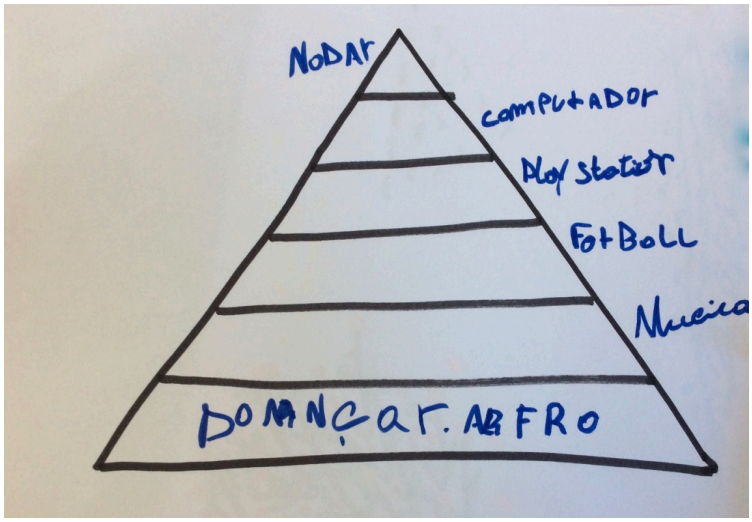

Figure 25. Fifth session, Alex 12 years old drawing his pyramid of needs

Eleonor

Eleonor was happy in this session. She is now the sister of her baby brother. The baby came home a few days ago, her father mentions and the situation at home is a little bit messy. The baby cries a lot, but Eleonor, has been a great help looking after her brother. She entered alone at the room, biting her thumbnail. Her father waited outside. She comfortable closed the door and waved to her father.

Regarding the task of the session, Eleonor didn't know how to draw a pyramid. At once she didn't say anything, waited a few minutes then, to my intervention she rushed saying that she didn't know how to draw it. I showed her on a paper

and then she copied the image on her paper. Also divided into five levels, Eleonor started to write on the peak of the pyramid ‘make friends' then she continued with drawing, then play with the baby at home and finally study/read.

> *"I like to study like my mother. She want me to have good grades at school, and I will have"*

Interestingly, Eleonor for the first time showed one of her difficulties and spotted it by putting it on the peak. Making friends, was not an easy task for her. She confessed that the only friend she have is Constança, her imaginary friend.

> *“Costança understands me. I like to be alone, but sometimes I like to talk to my friends at school.”*

On another level of the pyramid, Eleonor write Facebook. She claimed that her father uses facebook to meet some of his old friends he didn’t meet in such a long time. She enjoys spending time in front of the computer and listen to his stories.

Eleonor didn't know how to explain her difficulties making friends at school. She stays alone and her shy character is not helping her with her classmates. In continuity, we improvised some situation Eleonor likes to be alone versus having friends. The moment we improvised was related to her health condition. Eleonor shared that she would never confess to her classmates when she has low energy days because of her Anemia. She prefers to talk alone to Constança because with her she doesn’t need a lot of work to explain, cause her imaginary friends believes her. This improvisation, putted Eleonor in a difficult position, cause she had to imagine a situation, she would talk to one of her classmates. It took a lot of time between the pausing moments and biting the thumbnail. At the end of the exercise she urged to say:

> *“I became your friend… I think I am your friend?”*

Eleonor was starting to understand she needed friend in her everyday life. Constança was a result of her imagination to cover her loneliness. She became very nervous during the improvisation and many times paused and looked empty or posed her eyes on the ground. At the end of the session she left the

room without biting her thumbnails. Her father opened the door and she rushed to hug him strongly.

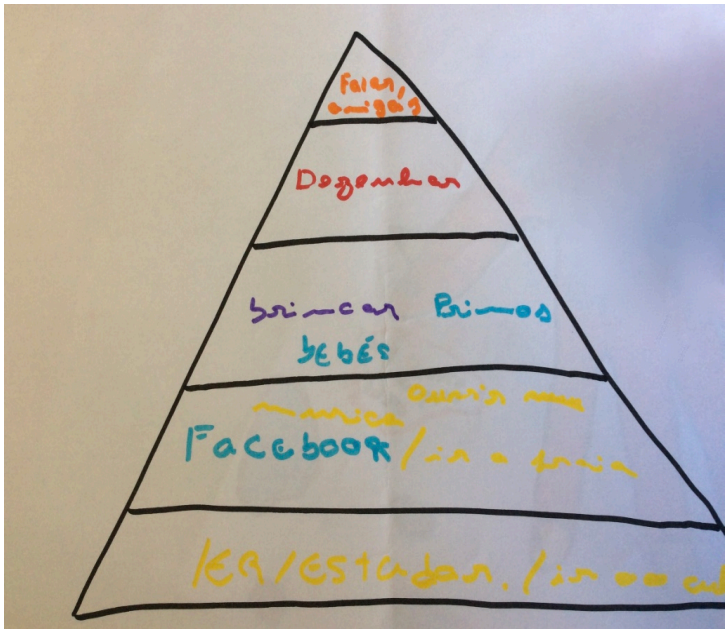

Figure 26: Eleonor 9 years old drawing the pyramid of needs on the fifth session

Vanessa

Vanessa was very happy. She entered the room very optimist, but a little bit sleepy, because now with the training she finally started 1 week ago, she spends long hours to practice herself and be always prepared. She

She sited in the usual chair. Her mother's presence didn't bother her on this session. Vanessa rushed describing her week of training, and all her new friends she made. She was daydreaming, and it was difficult invite her in another topic. She heard patiently the new task and drew the pyramid and divided it in five levels, and then added a new one on top. On the basic she wrote 'bla bla bla'. That was the song she had in mind from the first day she started the training and couldn't stop singing it. That was her happiness song.

> *"I do like to sing when I am happy…… I wrote bla bla bla because I like to be happy and to sing."*

In continuity, she just made the image of her father. That was the shape she would give to describe him.

> *"Sometimes I am scared of him, but I know that he loves me."*

Vanessa didn't want to talk more about her father, especially because her happiness would diminish and she didn't want to ruin it. So she started to sing the song she had in mind as a sign to bring back her happiness.

> *"I want to get married in a future… I want to have children…. I want to do things I like."*

On the third level from down she drew herself and her wishes. She confessed she liked the boy she met in the church.

> *"We sit together, we pray together. I like him….. but I am afraid if my mother discovers it, they will want to marry me."*

Her continued concern was the culture and the fear that her father would still want to marry her. She wrote at the peak of the pyramid finishing her training and then at the end of it concluded with having a job.

> *"Sometimes, I tell them I am sick so that they believe that I am not ready for marriage, at least till I finish the training."*

Vanessa still referred to the disease as her salvation achieving her goal. Although, differently rom the first session, she now has new objectives how to achieve her goal and her happiness describes she is succeeding little by little.

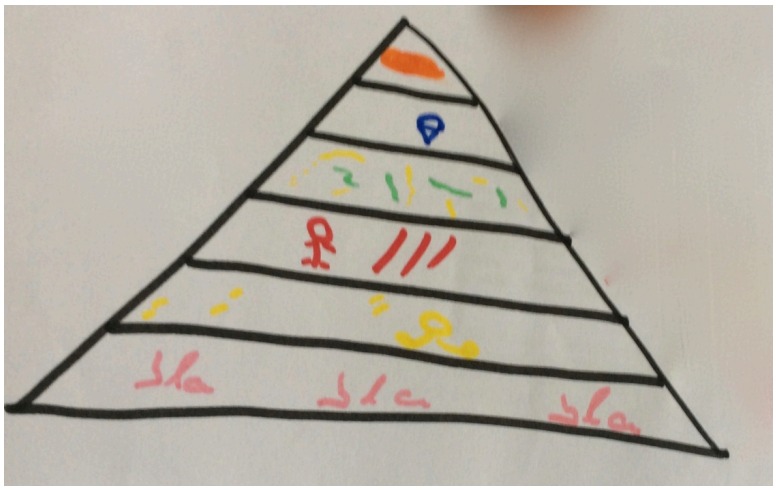

Figure 27: Vanessa 16 years old, drawing the pyramid of needs on the fifth session

Session 6

On the sixth session, the children had to draw an apple tree and position all the apples on the tree. Each of the apples symbolizes activities from the pyramid of needs and generating new coping strategies to face the problem.

Patricia

Patricia entered the room feeling enthusiastic. She was waiting impatiently to tell her news. She entered running in the room and sits smiling and waiting for me to join. Her friend invited her at home and they spent a very nice time together. They played with the dolls and puzzles. Her friends got surprised when Patricia finished the puzzle very fast. She mentioned that when staying alone at her room she liked to do puzzles and now its not difficult for her.

“They like me.”

Patricia this time didn't mention her insecurities, such as fat legs, or her fear that her friend will abandon her once knowing the disease. She feels uncomfortable share her health condition with her friends yet, but she was enjoying the moment.

"It looks like I am like them, I forgot that I had to come at the hospital, or that I feel sick. They like me."

She then became curious to listen to the new task for this time.

“When I come here, you tell me things and when I go home good things happen …. I like it.”

Patricia was referring to her success at school. Her teacher showed her homework in front of the class as an example and this increased her popularity. Now she has friends and is enjoying the new position. She took a paper and then immediately started to draw a tree. From the fifth session, on the table, there was already her last drawing with the pyramid of needs. She had to choose which of the activities she liked to put on the tree, also bring new ideas. She put the same activities as described on the pyramid of needs. Afterward, she wanted to put more details on her drawing and continued putting a house in the middle of the page and a person on the right corner of the page holding a flower.

Patricia- I like to have a big garden with flowers and trees.

R- And this girl next to the house, who is she? Does she have a name?

Patricia- Yes, that is me.

Patricia introduced the house as a barrier or intermediate to the tree and her wishes.

> *"My mother never lets me go to the swimming pool, she doesn't like that I stay out for a long time. My father doesn't like that I play a lot because I sweat and then I get sick……. My brother can play as much as he wants, but I can't."*

Patricia was introducing some details regarding her health conditions and her family protection.

Patricia- My mother puts so many clothes on me.

R- Why do you think she does it?

Patricia- Because she thinks that I am cold.

R- Are you cold?

Patricia- Sometimes… But if I have so many clothes then I sweat a lot.

R- Did you talk to your mother about the clothes?

Patricia- Yes, she says that I am little, and I can get sick very easy if I don't dress well.

R- And what do you think?

Patricia- When it's cold I get sick. Not always… but when it's sunny I don't like to wear so many clothes.

R- Then why do you think your mother thinks that you can get sick very easy?

Patricia- I don't know…maybe the doctor told her

R- You think the doctor said that you need to put many clothes to protect from getting sick.

Patricia- Yes, I think…but I look more fat like this.

R- You don’t like the clothes because they make you sweat, or they make you look fat?

Patricia- both…

R- And what happens if you get sick?

Patricia- I cough a lot, I have fever and, I have to stay at home…

R- So if you’re sick you can’t go to school, and can’t meet your friends.

Patricia- yes

R- If you had to choose between getting sick or the clothes, what would you like?

Patricia- (smiling) ufffaaaaa… I know what you are saying… but I look fat.

Patricia continued describing the house.

> *"There live four people in this house. My room is here on the second floor. Everybody is on the first floor watching TV. I am in my room."*

She introduced her house as a barrier to perform the activities she likes. Patricia once again mentioned her father as an important character in her stories.

> *"My family is careful, but my dad allows me sometimes go to the swimming pool. My mother doesn't like it, she get's mad, but then she forgets."*

Patricia struggled understanding how to deal with her health condition, using her family as an intermediate instead of a barrier to achieving her goals. At the end of the session she remembered her father was waiting outside. She helped to arrange the colors and then left the room.

Figure 28: Sixth Session, Patricia 7 years old, drawing a person and the apple tree

Ricardo

Ricardo entered the room feeling much better. His hands stopped trembling and he also stopped using the new medication. His health situation became stable and his family was very happy to hear the news. Ricardo as well was feeling very optimist. He was laughing again and started to tell about his plans for the next football match at the stadium. He went closer to the window and looked at the stadium imagining the next visit there.

When introduced the new subject to Ricardo, he happily took a paper and drew on it a big tree. His hand now were not trembling but he had more problems eye/hand coordination, and sometimes this would make him uncomfortable, especially at the school with his friends.

"I made a big tree…. Usually, the trunk is larger than the leaves."

Once again on the table, the drawing from the fifth session was on the table, and he was referring to it when drawing the apples. The most important were the football and the physical activity.

Ricardo- I know that I can never play football, I mean look at me…..

R- I see a boy that likes football a lot. When you come here, the first thing you do is looking at the window and see the stadium. And I see a boy that likes sport very much.

Ricardo- Yes, but I can't even run, or have the strength to hit the ball.

R- When you came here for the first time you were talking so passionately about Sporting and football. Do you like to watch the game as well, and talk about it?

Ricardo- Yes, when my father brings me to meet his friends we always discuss about football matches and they ask me about the results, because I know each of them.

R- Do you think this can keep you close to football?

Ricardo- Keep me close?

R- Playing football is not the only way to know about it, there are several other options.

Ricardo- like what?

R- You know all the records of your team, you like to talk about it. What can someone with so many abilities do?

Ricardo- nothing…. Well, my father says that he sometimes gets mad with the journalist that write about Sporting.

R- Do you think you can give a better opinion righting about sport?

Ricardo- Maybe….(smiling)

R- What else do you think can make you closer to the field?

Ricardo- Trainer? But they have to run, and be football player first…. I have nothing of this.

R- Do you think football players need special doctors to work with them?

Ricardo- Oh yes…. They also have to be in the field during the match…

R- Do you think that your health condition will stop you from doing these activities?

Ricardo- No, because I can write, I can read to learn how to do it, I know so many things about the bones…. Every time I meet the doctor I hear so many things.

R- Does this mean that you can find other options to do what you like? Your health conditions are closing one door but there are many other windows to open.

Ricardo- My father told me this once. But he always says that I will get better, and I get worst. I like this better… I know that I will never be able to run, but these other things I can do.

Ricardo was introducing himself into a new dimension of understanding his disease. Differently, from the other five sessions, Ricardo was very open to accept new ideas. Lately he forgot about the songs of David Carrera, but now he got himself inspired with new plans. Now he was developing new strategies to see his disease not only as a barrier to his dreams but as a condition to live with. Ricardo had a big smile on his face.

> *"Can I bring the next time something about football match, and you tell me how does it look?"*

He left the room smiling. This time he didn't stare at the stadium from the window . His mother worried was waiting for him when he opened the door. She was worried, but when she saw him smiling, hold his hand and headed to the nursery room for his treatment

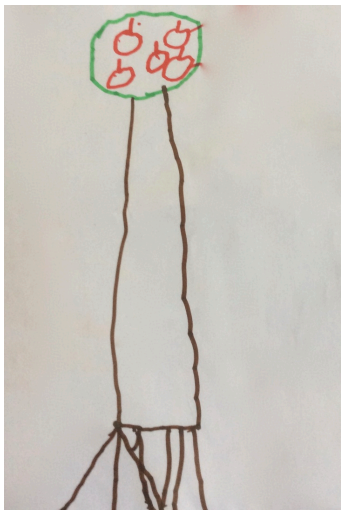

Figure 29: Sixth session, Ricardo 14 years old, drawing an apple tree

Luis

Luis entered the room happy. His football team won and he was glowing. He was very happy because for the first timetime, he played the entire game, not only one-half. This gave him courage. He listened patiently to the subject of the session and as usual, he likes to be different from what is asked, and he drew a tree divided into three parts. The most important part was football. Later on he filled one part of the tree with a football field. Then he mentioned his family as the one coming immediately after and would also profit immensely from this opportunity.

At this moment Luis was not considering his disease as a problem any more, mainly because he had achieved success with the remedies his doctor gave him to deal with the pain. Although, Luis was not ready to deal with a situation when his disease would impede him to achieve his goal.

R- Do you think you can become a famous football player?

Luis- Yes, I think I can.

R- That requires a lot of time, training. It is a very hard work. It is not going to be easy.

Luis- I know, but I train every day at home. I play with my friends, and that is the best training.

R- Sometimes it needs more that just a play with friends to be professional. But I like your enthusiasm, and that will help you.

Luis- I can do it.

R- I like to make a game. Let's imagine for one moment that you achieve your dream. Someone sees you play vey good football and picks you to train on his team. How do you think that will be?

Luis- Ohh that would be amazing. I mean that's the dream of everyone.

R- And what will happen if at some point you start to feel sick and not play?

Luis- Oh no that can not happen. I will take care of myself.

R- Well, let's just think as a chance, because before you were feeling sick as well.

Luis- This sickness has stopped me from many things but not this time.

R- Your health conditions are very important. What would you choose under this condition?

Luis- Ufffaaaa…. I don't want to think that. Why would I think the worst?

R- Ok, so what is the worst that can happen?

Luis- I will stop playing… I guess.

R- How would that make you feel?

Luis- I already feel like there is nothing else I can do. You made me feel sad now…

R- I don't want you to feel sad. I want you to understand your health conditions and also to keep in mind that accepting them helped you already once.

Luis- What do you mean?

R- Well, before you were having a lot of pain, but then you understood that this is your health situation and found a solution. Do you remember what that was?

Luis- I asked a doctor (smiling)

R- Yes you asked a doctor, and you found a new way to do things you like to do.

Luis- I forgot that…. You are strange.

R- Is it good or bad to be strange?

Luis- no, is good of course… I never understand why you ask me something, and then at the end, you tell me something else, and I think, why didn't I think of that before? (smiling)

Luis continued talking about his family and how they would be happy and proud of his success. This time Luis was attentive to dream.

“This is funny…. Now when I think something, I think what would you say.”

Luis left the room after putting the colors in order and went to the room where he was going to take his treatment.

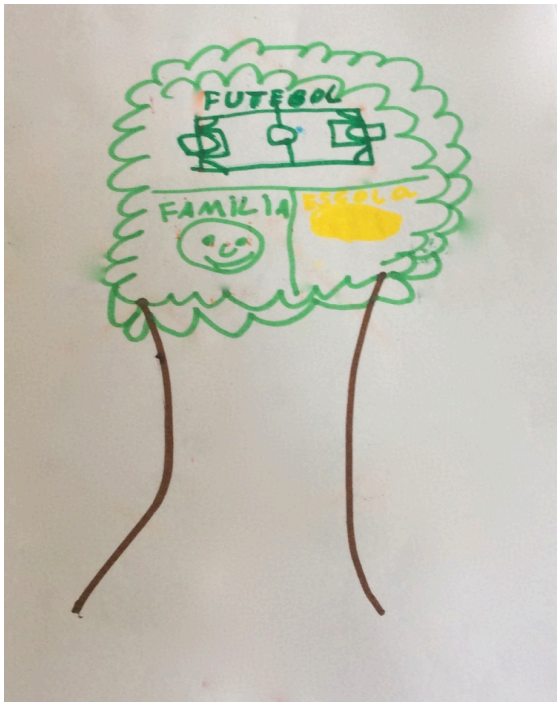

Figure 30: Sixth session, Luis 12 years old, drawing an apple tree

Alex

Alex as usually came with a new song. This time he decided to prepare an African song. He asked for my permission and started to sing. In the end, he also translated the lyrics. It was a happy song, showing that when you are happy you can't stay sited but you need to dance.

After finishing his song he listened attentively to the task of the session and putted many colors on the paper. He did his typical tree with many branches and put many colors around. On the right side of the paper also created a small river. Alex didn't want to put a few apples, but fill it with many instead.

"This tree now has grown up and had flowers."

He was referring to the pyramid of needs drawing and nominated only two apples. One was for the music and the other one for the African dances.

Alex- Now I can dance. Well, I am not very good at singing yet, but I feel good singing.

R- Do you have more pain when you dance?

Alex- Yes I do, but I learned just the steps that are not very difficult.

R- That is very good.

Alex- The other time when you left after we met in this room, I met a girl. Wait I don't remember her name. Oh yes, Vanessa.

R- Yes, Vanessa also draws with me.

Alex- She was sited next to me, and drawing. You told her that I draw very good and she asked me if I could help.

R- Yes I told her that you draw very good. Do you think I did wrong?

Alex- No, of course (smiling). We drew together. I showed her how to draw the trees, and the birds.

R- Did you like to draw with her?

Alex- Yes, I mean it was different.

R- Do you like to do this better than listening alone to your music?

Alex- Maybe. But the educators were looking strange that I was talking to Vanessa.

R- I am happy you liked it. I would like to see your drawing.

Alex- Vanessa has it. She said that she would bring it for you when she meets you.

Alex talked longer about the work they did together, and also he expressed his enthusiasm to repeat that would repeat it again. Spending time with someone, helped Alex to introduce himself to others and also display his abilities. Alex was happy, cause Vanessa showed how talented he was. That gave him confidence. His drawing for this session was the same as he did with Vanessa. He took longer now to draw and fill it with as many details as possible. The tree once had no leaves when he drew on the third session and now this one is a

spring time. The tree is flourished, birds are singing around and the water is near.

> "*The tree now is not alone …. Birds can talk to tree…. The water, to fresh it when it hot…… some leaves are falling, but that's good…. I like to play with the fallen leaves."*

Alex, seem to be more confident to talk to people and trust more in himself. He left the room promising to sing another African song the next time and also

Figure 31: Sixth session, Alex 12 years old, drawing an apple tree

Eleonor

Eleonor was sleepy when she entered. Her father took her to the hospital because her mother was at home taking care of her baby brother. She began biting her thumbnail but didn't hold her dad's hand. She sat comfortably in the chair and was looking around with her eyes tired. Eleonor started to talk about her brother and how much he cries without waiting for my invitation. It was the first time she open a conversation. She loves her brother, but sometimes he doesn't let her sleep well at night, she said.

> *"My mother is with him all the time, and I rarely speak with her."*

Eleonor saw on the table her last drawing with the pyramid of needs and was looking puzzled what was the next task. She, took the brown color and started to draw the tree and then filled it with many apples. Her needs and wishes now have expanded. She was very careful with the details of the drawings. The tree was small and she putted to very big flowers nest to the tree. On the right side of the tree she wanted to draw something else but then her hand got tired and didn't finish it.

> *"The flowers are big… this gray here, don't look at it, I don't know what I had in mind, but I don't like it now."*
>
> *"I talked to a friend from school…. It was not so difficult to do."*

Eleonor- I talked to a girls sited near me.

R- How did you feel?

Eleonor- I don't know…

R- Did you like it?

Eleonor- I liked also being alone

R- You also like to have friends? That is what you wrote in your drawing.

Eleonor- Yes, but she talks a lot. I just wanted to ask her something, and she didn't stop talking.

R- And what did you do?

Eleonor- I didn't listen to her. I let her talk.

R- What would Constança do?

Eleonor- I don't know…. Maybe change discussion?

R- Do you think this would have helped you too?

Elenor- I don't know….. Maybe she would talk again a lot more.

Eleonor wants to have friends but she feels safe in her shelf. She feels uncomfortable and unable to appropriately adapt to different situation. Her

imaginary friend, Contança on many occasions helped Eleonor feel better and take the courage to open to social interaction.

At the end of the session, she contributed putting the colors back in order and run to her father.

> *"We have to go home earlier today. My mother needs us to help with the baby."*

Eleonor did her first step talking to a friend. The drawing, describes her more confident with the colors and the shapes. She was very careful and didn't as for suggestion to chose the color.

Figure 32: Sixth session, Eleonor 9 years old, drawing an apple tree

Vanessa

Vanessa entered in a rush and showed me immediately the drawing she made with Alex. She opened the paper on the table and added:

> *"I really liked these days spent with you in the sessions. I enjoyed not to have my mother attached to me all the time, enjoyed to talk, sometimes even about stupid things (laughing) like the clothes that I like to try. Ummmm … I also liked meeting Alex. Before I wouldn't have done that, going to talk to someone, I don't know. But knowing that he knew you, I felt already close and asked him to draw. I*

mean…. Everybody is doing that in the other room with the kids. Plus it was interesting to see my mother not opposing to talk to Alex for drawing… she usually does."

When I introduced the task of the session, Vanessa shared another detail of the meeting with Alex.

"Alex showed me a new technique how to draw trees, and is so interesting. The next time I am going to see him around, I'll ask him again to draw with me so that I can learn something more."

Vanessa started to imitate the same tree she drew with Alex and trying to make it as identical as possible. It took her some time to satisfy her taste.

“My training is going so good. I like what I am doing. I stay a little bit longer, because I know how to learn better, but I don’t get easily tired….. My mother comes to pick me up. She comes earlier, so I let her wait till I finish. Now she calls before coming.”

Vanessa started to put more and more details to the drawing but at the end was not the same as the one they did together with Alex. She was feeling disappointed but didn't say anything. She discussed more about her church events and the meetings with her friends. Now she is becoming more independent, and not afraid to share her cultural traditions with her friends.

She also shared her training schedule and counted the days till the final exam.. Vanessa was so proud of the drawing she prepared with Alex.

“*I want you to keep this drawing. Alex wanted me to show you, and I want you to keep it. I already have a picture of it, and I am sure I will meet Alex again and draw with him."*

She arranged the color at the end of the session and got ready to leave and meet her mother. On these last sessions, she didn't mention her mother many times, just randomly describing the feeling of independence without her presence. For this reason, she was less aggressive with her mother.

Figure 33: Sixth session, Alex 12 years old and Vanessa 16 years old drawing an apple tree

Session 7

On the last session, the child is led to the main subject of the test "Person picking an apple from the tree." In this session the conversation with the child is limited, to contain to the ethic principles of the art intervention.

Patricia

Patricia was happy today. She came at the hospital as usually with her father. Her brother was at school, and she was happier because she could have all the attention for herself. They came early, had breakfast, and were playing a game on the phone. Patricia didn't feel very happy to leave her father alone, although, she came into the room, and her face started to smile again.

When she positioned herself on the chair, I introduced Patricia with the task of the session and also explained her this was going to be the last art session. She already knew there were going to be 7 sessions, but didn't expect this to be the last session, but she didn't give any reaction. She was more focused on the drawing she was going to do. I approached a paper and the colors in front of

her, and she started to pick the colors. Firstly, she took the brown color and began to do the trunk of the tree. Then when she took the green color, she stopped and asked:

"But I am going to come here again? ….. But I liked drawing…. It's boring alone here… I could talk to you."

Patricia was confused and didn't expect this to be the last time coming at the room drawing. She stopped for a while and then continued to draw the upper part of the tree.

"You told me last time that we are going to have the last meeting, but I thought that I can still come to talk to you."

Then without saying anything, she continued finishing her task. On the left corner of the page, she put the tree and herself at the same height of the tree, holding an apple in hand, with the arms wide open. Patricia left the color on the table and showed me the drawing.

"I think I can draw better now…. My teacher showed again my notebook in front of the class. I am writing better."

…..

"Will you come again to the hospital?.... I will miss you!...."

Patricia was conscious about here changes from the first session to the last one. Through the exercises we made, she now holds better the pencil on her hand, doesn't come approach very close to the paper and is finally making friends. There are still some moments when she lack confidence that she won't be able to keep with the good work. Patricia, now doesn't spend more time alone on her room, but interacts with her family as well as her friends. In the drawing, Patricia holds the apple in her hand. She drew herself almost at the same size as the tree and reaching the apple was an easy talks. Her face in the drawing is happy, her arms are open as she is exited to show the apple and attract attention.

At the end of the session, helped me put the colors on the case and before going out she gave me a hug. She runs to the door to meet her father who was standing alone, waiting for Patricia's treatment.

Figure 34: Seventh session, Patricia 7 years old drawing the PPAT test

Ricardo

Ricardo entered slowly and was holding a paper in his left hand. He gave me a smile and sat on his chair. Without saying a word, he unfolded the paper and showed me a drawing.

> *"This is for you…. I know this is the last session and I wanted you to have something from me. ….. This is me playing football. I started to write also something about a football match, but I forgot it at home."*

Figure 35: Seventh session, Ricardo 14 years old drawing, himself playing football

Ricardo drew himself playing football. The drawing was on the right corner of the big paper. He was very proud of his work.

> *"It took me a lot of time to finish this drawing, because I was doing a lot of exercises for my hand. I stopped five times, but I did it, and I was very careful not to draw outside the border."*

After explaining the last task, Ricardo was looking again from the window, staring at the stadium.

> *"I can't see the stadium from the other room. Thank you!…. My parents are so happy with me. I told them what I like to do and this thing will keep me busy. They like to see me when I do something I like, and they are supporting me."*

Ricardo started to draw the task of the last session PPAT, and this time he didn't wait for me to ask for a pause when he needed to relax his hands. He paused four times. His hands were not shaking any more. Ricardo still could not control the strength to hold the pencil and the contact with the paper. Although, he was controlling better the length of the lines, also filling the colors inside the lines.

> *"I think this you will like it better. I am tall, and I think I can reach the apple…… Well, I think I can take just some of them, but I am happy, as long as I am close to football. Now I will write about football."*

Ricardo drew a long tree especially because he couldn’t control his hand when to stop. Then the size of the green leaves on top, it was very little. He drew four big apples and his hand is somewhere hidden among the leaves of the tree, without showing whether he picked the apple or not. His strategy to pick the apple, was to drew himself tall enough at the height of the tree. He then explained:

> *“My grandmother reads the bible. She told me that the apple trees have the apples very low, easily to reach by hand.”*

This was his perception of the tree and why he drew himself almost at the same height. His hand is hidden somewhere and he describes it as:

“The apples that are inside the tree are better. The other one of the surface everybody can reach them.”

Ricardo left the room, waiting till the last moment, for his mother to knock on the door and to pick him up. She shook hands with me and added:

"I am very happy; you helped Ricardo. Every time he met you, he was coming with a new idea and was happy at home. I am sorry he will not meet you any more."

Figure 36: Seventh session, Ricardo 14 years old drawing PPAT

Luis

Luis entered the room a upset and didn't want to talk. He just sat on the chair and was looking at me for the task. After explaining the task, he smiled and took the paper ready to draw.

"I know you are going to leave…. But I will continue coming here to the hospital."

Luis didn't elaborate his sentence. He started drawing a big sky filling most of the paper and then the sea on the left side of the paper. Then he filled with the grass and drew a brown small house. Right on the left side of the house he drew the tree and filled it with apples. After that, he was not sure where to put

the person. He looked around and stood up. He was lost in his thoughts when was drawing the water and didn't rationalize the space. In 1 minute he returned to his chair. Immediately he added a chair in his drawing and the person climbing the chair to pick the apple. The hand of the person is inside the tree holding the apple ready to pick.

> *"You were right the other time… sometimes I dream a lot….. the other game I had I couldn't continue the for the entire match running."*

I encouraged him to talk more about his choice of drawing and why did he put the ocean/sea.

"I guess I drew the ocean cause, I always feel is so big…. It looks calm, but you never know it may take you deep…. I once remember I was with my mother and was swimming. I thought I could go deeper cause it was warm and calm, but then if it wasn't for my mother I don't know what would have happened."

Luis Imagined the ocean to be like himself. At the surface when he is happy he starts to dream big and have a lot of hopes but later on when he sees the reality and his own abilities he gets disappointed. In the drawing, he also joined a chair to pick the apple.

> *"I liked you…… I don't like that you're going…. I will continue coming to the hospital…… Now I can play football longer. I putted the chair cause it reminds me of this you."*

Luis kept mentioning that he will continue to visit the hospital. His silent revolt now had a voice. He didn't accept yet that his health condition is chronic and this requires visiting the hospital continuously. In the middle of his phrases, he was mentioning his attitude toward the art intervention.

Luis finished his drawing. He didn't want to leave the room at once. He stood up and walked around for a while then with a smile asked if I wanted help to arrange the colors and the room. He helped without saying anything. Then he asked me if I could walk with him to the waiting room where his mother and grandmother were. As soon as we arrived there, the nurse called his name for the treatment. He gave me a smile and sat in the chair for the injection.

Figure 37: Luis 12 years old drawing PPAT at the seventh session

Alex

Alex had prepared an African song to sing. He entered in a rush, sat down and immediately put the music so I could hear. He started to sing along with the music and was looking at me while singing.

> *"This is a song of a man that after being sad that his girlfriend left, now is better, and is looking for things to do that will make him happy again."*

Alex gave a hidden message about himself. Every time I was trying to explain that it was the last session, he was interrupting me with the music and its lyrics. Then he waited till I explained the last session's task.

> *"I am going to do something very beautiful."*

He drew a tree at the beginning and started to create the branches full of leaves and apples. The tree became very big and then a short person. Then he filled the entire paper with green symbolizing the grass. The tree was not alone, was surrounded by many other small tress and on top of it some birds flying. The person was very small, almost unnoticeable among the grass and his right hand lifted high to reach the tree. Alex didn't reach the apple, but was trying to get closer to it

“The grass is beautiful, means that the earth is healthy and its summer. ….. My tree, the apple tree is not alone, has other friends that can talk to it sometimes when its alone.”

He smiled and was looking for other details to put in his drawings. Happy at the end he showed me the drawing.

"This is better than the one I did with Vanessa. …. The educators that know me they were looking surprised to see me talk to someone. Now that they saw my drawing, they are asking me to draw, and they hang the paper on the wall. …. It's nice, yes, but I like to dance and sing too."

Alex was describing his situation now at the hospital.

“I remember, when I started to dance with you my mother noticed me…. And now the educators as well.”

He was being recognized, that was explained also his drawing. The person lost in the green, and trying to get out of the invisibility and reach his goal. The task was not easy for Alex, but at the end he putted another detail very important. One apple was very close to his hand, although he didn’t manage to pick it.

Figure 38: Seventh session, Alex 12 years old, drawing PPAT

Eleonor

Eleonor came as usual with her father. She was very shy today entering the room and didn't want to leave her father's hand. He entered and sat next to her. She continued to bite her thumbnail. To my invitation to spend some time alone, she smiled and didn't oppose. Also when her father stood up to leave, she didn't react, but saw him leaving the room sitting just on the border of the chair.

I explained to Eleonor the session, also reminded that this was the last session and as such we still had one more day to enjoy some drawing and spend some time together. She listened till the end without saying a word. When I showed the color and the paper in front of her she sat comfortably on the chair and stopped biting her thumbnail.

Shy, again she needed to explain the task again. She listened again then reached for the brown color. Continued her work adding the part of the green and just four apples on it. Then very simply added a person on the left of the tree stretching the arm to reach the apple.

> *"I don't have such long arm, but when I watched the cartoon, they always can extend their arms to catches things that are very far."*

Eleonor continued drawing without saying anything about her work and at the end was looking at it closely. To my invitation to describe her drawing, she smiled. She was still living in an imaginary world, without accepting the reality. The tree was not prefect, and the colors to feel the green part of the tree didn't have a good quality, but she was happy with this result. Then for drawing of the person she asked if she could use colorful pencils. She reach for those and drew a blond girl reaching to pick an apple the girl hold in her hand. The girl looks happy and is in the center of the page.

> *"Well…. If I was near the tree,, not a drawing, I couldn't stretch my arm so much. I don't know what I would do…. Maybe …. I would use a chair."*

Eleonor added the sun on top of the tree. During the seven sessions Eleonor became very opened and intervened during the discussions and drawing tasks.

She created a new friendship connection and now this circle had to end. She finally started to talk to her friends and started for the first time to build a connection with someone who was not her family member and knowing that this connection made her anxious reason why she entered holding her father's hand and biting her thumbnail.

> *"I don't want you to go….. when I come at the hospital I forget anything because I know that first I will come here."*

Eleonor confessed for the first time this connection she had with the sessions and the freedom she gained discussing and drawing. The time was passing and she was looking at the clock very often. When her father knocked on the door she didn't bite her thumbnails but she stood sited on the chair longer. Her father waited for her, till she helped me arrange the colors and then she took her father's hand and left.

Figure 39: Eleonor 9 years old, drawing PPAT in the 7th session

Vanessa

Vanessa entered confident into the room with a big smile. She sat on the chair telling her week and especially about her training and the new techniques she learned. Then she showed her nails, with a different style she learned at the school.

After describing her improvements in the training, she was looking at me for to give the introduction of the session. She listened till the end of the explanation and then happy added:

“I have a great idea for this.”

She took the colors on the table and started to draw a tree and used the same technique as the one she used with Alex the other time. In the end, she drew a person climbing the tree to stretching the arm to reach the apple. Vanessa didn't think too much; she already knew what the strategy to pick the apple and immediately took the colors to draw herself climbing the tree was. She didn’t draw the entire tree, just one part of it and a person climbing on the lower branch. Differently form the last time of drawing with Alex, they met again in the waiting room and had been taking some other tips on how to draw. She was happy to see the result as the tree now looked better. She had some difficulties drawing the person climbing, changing the position of the paper many times. At the end she added:

"I will catch that Apple…. I mean, some apples grow low on the tree."

Vanessa at the end of her drawing, happy with her result ended:

“So this is the last time we are going to draw together!..... I will miss you, mainly also because you helped me. Thank you!”

She stood up and run for a hug. She helped with the colors and then with a smile left the room, going to meet her mother, as usually waiting outside for her.

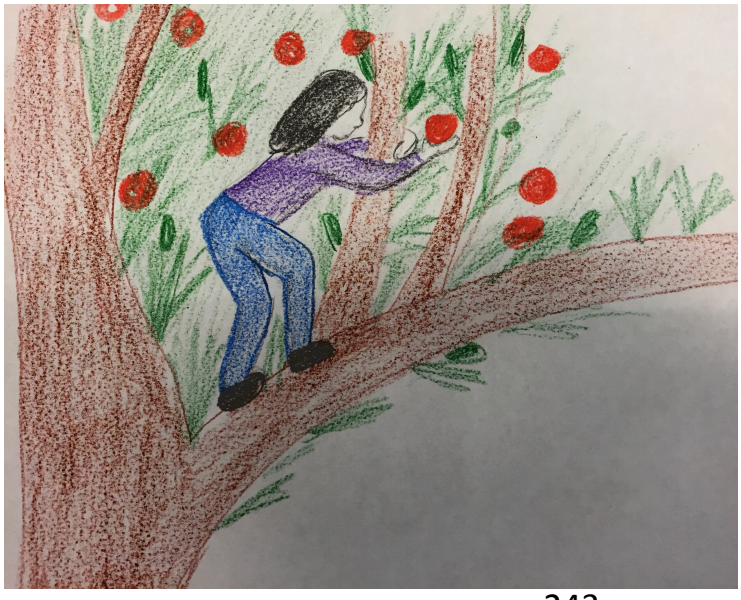

Figure 40: Vanessa 16-year-old, drawing the PPAT in the 7th session

3.5. Results from the Person Picking an Apple from the Tree (PPAT) test for the participants of the experimental group in the 7th session

The seventh session of the art intervention administered the PPAT. Six children from the experimental group underwent the intervention, while the six children in the comparative group continued their normal routine at the hospital. Based on the FEALTS scores, the PPAT has 14 variables. The eighth variable is the Problem Solving (picking the apple from the tree). As described in table 18, all the drawings from the seventh session were analyzed using FEATS score.

The PPAT assessment test identified the coping strategies children would refer to "pick" the apple, and generate new strategies to find a solution. The 8th variable "Problem Solving" scale corresponds to the main goal of the test, assesses the effectiveness of art intervention ranged from 1, "The person does not have the apple in hand, or there are no apples on the tree or on the ground" to 5, "The person is on the ground, or some other reasonable type of support such as a ladder or rock, or is standing on the ground with arms extended, and the Apple is actually in hand." Table 19 presents the criteria for scoring and frequency for participants.

Table 18. Mean and Standard Deviation for the PPAT scales for the participants in the art intervention from the 7th session

FEATS Score N=6	Mean	Standard deviation
Prominence color	3.8	1.17
Color Fit	4.7	0.82
Implied energy	3.3	1.03
Space	1.8	0.41
Integration	3.5	0.54
Logic	4	0.63
Realism	3	1.26
Problem solving	3.66	1.03
Development level	4.5	0.55
Details of objects	2.7	1.36
Line quality	3	1.54
Person	2.8	1.17
Rotation	4.7	0.82
Preservation	4.8	0.41

Nearly 1 participant out of six scored five on this scale. Surprisingly, from the course of the sessions, Alex still finds it difficult to cope freely with the problem

he encounters. He appears to be in a field with grass and a big tree with some apple on it, surrounded by many other trees. He stretches his hand to catch something, but he doesn't reach an apple. Although scores are not assigned a category, Gantt and Tabone (1998) implied that depressed individuals would be unable to see the obvious potential in a situation. According to this interpretation, the majority of the participants were resourceful, indicating adequate coping ability.

The middle score was only in two cases rated 4 on the Problem-Solving scale. The person appears to pick the apple, but the solution they found was not reasonable. It mainly included drawing a very long arm to reach the height of the tree and the apple. Such was Luis and Vanessa. The two of them appear to stretch their hands near the tree and grasp the apple. Their solution seems unrealistic, as they imagine themselves big enough to pick the apple despite the height. In the case of Vanessa, she decided to climb the tree and pick the apple. Interestingly, in the case of Eleonor, her score is 3. She appears to be standing on the ground reaching for the apple. Her fingers are touching the apple but don't look like she has picked the apple from the tree.

Differently, in the case of Ricardo, with a score of 2, he reaches a hand near a very tall tree with four apples. His hand seems to get lost among the leaves and doesn’t appear clearly whether he is grasping the apple or not.

Table 19. 'Descriptive frequency and percentage of assimilation of Problem solving' scale from the PPAT test

Scores	Characteristics	Cases (N=6) f (%)
0	Tree, apple, and/or person missing or cannot be identified	0 (0)
1	Person does not have the apple in hand, or no apples in a container or the ground	1 (0.16) Alex
2	Person has apple in hand but not apparent how he/she got it, or apples appear to be falling into container or on ground or person.	1 (0.16) Ricardo
3	Person appears to have picked apple, but solution is unreasonable	1 (0.16) Eleonor
4	Person on the ground or other reasonable type of support and is reaching for the apple	2 (0.5) Luis, Vanessa
5	Person on the ground or other reasonable type of support or standing on ground with arm extended and apple in hand	1 (0.16) Patricia
	Total	6 (100%)

A higher score on the problem-Solving Scale is one child scoring 5. Patricia was the one generating an interesting solution to pick the apple. She has her arms open, standing on the ground, holding the apple in her hand. To rate a 5, the person must be on the ground or some other reasonable type of support, and the Apple must appear in hand.

In addition to the quantitative data, a great deal of useful information was obtained from observations of participants in the art intervention sessions. The PPAT symbolic content rating system comprises 9 Likert scales. The scales range between 0 to 5 or 6. A zero scores means that the relevant object is missing from the drawing (e.g., tree, person, or both). Each scale measures one of three characters: trees, persons, and the person-tree relationship. The table 20 describes the Mean and SD for each of the scales of the SC-PPAT.

Table 20: Descriptive statistic of the SC-PPAT symbolic content for the PPAT (Bat et.al., 2014)

Scale no.	Measure	Points on Likert scale	Score 1	Score 5 or 6	Mean N=6	SD N=6
1	Number of apples on the tree	6	A tree with no apples	A tree with more than 10 apples	4.6	0.81
2	Tree's strength vs. weakness	5	A very weak tree (more than 3 weakness indicators)	A very strong tree (more than 3 strength indicators)	3.3	1.36
3	The degree to which the person is active in apple picking	6	The person clearly avoids picking (e.g., turned in another direction)	The person is clearly active in the picking process, plus stands on a heightening object	3.5	1.37
4	Degree of success in picking the apple	5	There is no contact between the person and an apple and there is a great distance between them, or no apple on the tree	The person holds one or more apples, disconnected from the tree	3.1	1.16
5	Contact between the person and the tree	5	No contact between the person than the tree	Person is contained within the contours of the tree	2.6	1.75
6	Height ratio between the person and the tree	6	The person is significantly shorter than the tree (1:5)	The person is taller than the tree (2:1)	2.8	0.75
7	Position of tree trunk in relation to the person	5	The tree trunk is clearly inclined away from the person	The tree trunk is clearly inclined toward the person	3	0.89
8	Branch placement in relation to the person (close vs. far)	5	Branches or treetop are inclined away from the person	Branches are coming out of trunk towards the person (the tree is making an extreme effort to be helpful)	3	1.09
9	The extent to which apples are distributed on the tree, either close or far from the person	5	All apples are placed on the side farther from the person (even of there is a single apple)	All apples are placed on the side closed to the person (even if there is a single apple	2.5	0.83

For the cases of Patricia, Eleonor, and Ricardo, their drawings had many elements in common. For a 7-10 year old child drawing should typically include

a baseline and/or skyline, with bodies that are complete and show a neck, trunk, and separation between arms and hands, with parts that are beginning to the proportional to one another. The three drawings of PPAR describe a passive person standing next to the tree. Patricia drew a person with a distorted body parts, standing very far from the tree holding an apple on her hand. Her drawing doesn't describe how did she pick the apple. The tree has only four apples on it and they are not close to her side. The apple is just a circle with no filling. The drawing is very small in the A4 format paper. The trunk is straight, in the middle of the paper, while the person stands on the left side of the tree.
Eleonor and Ricardo drew a person standing far from the tree but stretching the arm very far to reach the apple. Their hand is lost among the tree leaves and doesn't specifically describe if they manage to pick the apple or not. For a 11-14 year old the drawing should show overlapping objects, realistic proportions size among objects, and complete bodies with well-defined joints and limbs. Ricardo drew a person trembling, illustrating a shaking arm and leg reaching for the apple. The tree doesn't have branches but is a container with only 4 apples. As regarding to Eleonor, she drew a smiling person reaching for the apple. The distance between the person and the tree illustrates an unrealistic scene.

The other 3 children, Luis, Alex, and Vanessa performed a more complicated. Luis and Alex preferred to add other details such as the sea for Luis and a big field for Alex. Vanessa, differently, illustrated a very small person climbing the branch of tree picking the apple. The tree illustration is appropriate to her chronological age, containing 10 apples, and many of them next to her. She didn't draw the entire tree, just a few branches leaned on the right side of the paper. The drawing started on the left low corner of the paper, filling almost the entire page. In relation to the branch she illustrated a correct size proportion, although, the big tree stands on the other side she didn't prefer to draw.
Alex on the other side, drew a big tree with 10 apples in the middle of the paper, and then fills the paper with many other small trees in the background, a field of grass and a very small person compared to the size of the tree. He preferred to use a shaper for the apples to look perfect and of the same size. Luis added water next to the tree. He drew the tree on the right side of the paper containing

more than 10 apples. He added a person standing on a chair and stretching both hands to pick the apple. The three of them illustrate a person in action, showing only the back of body. Vanessa differently, shows a smiling face on one side while climbing a tree.

The study found that the formal elements of the sample drawing indicated, on average, a lower than adolescents drawing level. The majority of the drawing were rated 3 and below from the 9th Likert scale of the SC-PPAT. Participants in the study did not receive feedback about their images, not were they clinically assess on the bases of their drawings.

3.6. Results from the Adolescent Pediatric Pain Tool (APPT) for both groups after the art intervention

The second round of the questionnaires was administered immediately after the last session of the art intervention for all the children in the experimental group. Regarding the Adolescent Pediatric Pain Tool (APPT), the results for both groups didn't have many changes in their replies, as the pain is chronic (Table 21). Although, in the case of Ricardo, he changed his perception drastically for ‘affective' pain description from (0.09) to (0.36). As well as in the case of Vanessa, she increased her self-awareness, evaluating her pain as more ‘Temporal' from (0.18) to (0.36). Finally, for Eleonor, her confidence describing pain helped her commit more to evaluate the right level of pain. She has a medium level of pain, as such, her pain perception showed an increase in all four descriptive pain classifications.

The same conclusions go for the comparative group. The questionnaire was administered simultaneously with the experimental group. As described in table 22 below, all children had very few differences from the first administration. For Mariana, her description of pain leans more on the ‘Temporal' level with a change from (0.09) to (0.45). The contrary happened with Bernardo, changing the ‘Sensory' descriptive pain from (0.65) to (0.32).

Table 21. Descriptive data statistics from the APPT for the experiment group after the art intervention (N=6)

	Pain Location	Pain Intensity	Sensory	Affective	Evaluative	Temporal	Total
Patricia	Head- 2 cm Hand- 1cm Feet – 1 cm Back – 3 cm Neck – 0.5 cm	High level of pain	0.08%	0.09 %	0.37%	0.27%	0.15%
Alex	Head – 1 cm Shoulder – 3 cm Left leg – 7 cm	High level of pain	0.13 %	0.27%	0.62%	0.09%	0.21%
Ricardo	Head – 2 cm Legs – 7 cm (each) Arm – 3 cm (each)	High level of pain	0.24%	0.36%	0.37%	0.09%	0.25%
Luis	Chest – 3 cm Head – 1 cm Shoulder – 2 cm Knee – 0.5% Pulse – 1 cm	Medium level of pain	0.29%	0.09%	0.25%	0.36%	0.24%
Vanessa	Back – 2 cm Pulse – 1 cm Menstruation pain	Medium level of pain	0.05%	0%	0.12%	0.36%	0.1%
Eleonor	Head - 1 cm Left hand – 1 cm Chest – 2 cm Feet – 1 cm (each)	Medium level of pain	0.27%	0.27%	0.25%	0.36%	0.28%

Table 22. Descriptive data statistics from the APPT for the comparative group after the art intervention (N=6)

	Pain Location	Pain Intensity	Sensory	Affective	Evaluative	Temporal	Total
Bernardo	Shoulder – 3 cm Head – 2 cm Feet – 1 cm (each)	High level of pain	0.32%	0.36%	0.63%	0.27%	0.36%
Mariana	Left arm – 3 cm Feet – 1 cm (each) Arm – 1 cm	Medium level of pain	0.13%	0.18%	0.37%	0.45%	0.22%
Pedro	Head – 1 cm Shoulder – 2 cm Stomach – 2 cm	Medium level of pain	0.21%%	0.09%	0.12%	0.36%	0.21%
Liliana	Chest - 2 cm Right leg – 2 cm Right shoulder – 1 cm Neck – 1 cm Eyes – 0.5 cm	Medium level of pain	0.11%	0.09 %	0.5%	0.36%	0.19%
Cristiano	Neck – 1 cm Stomach – 2 cm Left leg – 5 cm Shoulder – 3 cm	High level of pain	0.24%	0.45%	0.37%	0.45%	0.33%
Carla	Head – 2 cm Eyes – 1 cm Neck – 1 cm Arms – 3 cm (each) Right leg – 2 cm	Medium level of pain	0.16%	0.09%	0.12%	0.36%	0.18%

The table below describes more in details the children's frequency of descriptive pain words after the art intervention. They are merged in one table, following the same description as the results at the baseline in order to compare both groups.

Without any surprise, their detailed map of pain words continues the same as before. Starting with the category of “Sensitive” descriptive words like “suffocating, screaming, frightening, pressure, and sore.” In this category there are no noticeable changes. Although, ‘hurting' has an increase from f=0.02 to f=0.13, different from “awful” from the “Affective” descriptive pain words decreasing from f=0.54 to f=0.27.

Table 23. Frequency of the descriptive pain word selection for each subscale of pain classification for both groups after the art intervention (N=12)

	Sensory	Affective	Evaluative	Temporal
Aching	0,02			
Hurting	0,13			
Like an ache	0,05			
Like a hurt	0,02			
Sore	0.21			
Beating	0,16			
Hitting	0			
Pounding	0			
Punching	0			
Throbbing	0.16			
Biting	0			
Cutting	0.05			
Like a pain	0			
Like a sharp knife	0			
Pin like	0			
Sharp	0.05			
Stabbing	0.18			
Blistering	0			
Burning	0.13			
Hot	0.21			
Cramping	0			
Crushing	0			
Like a pinch	0			
Pinching	0.05			
Pressure	0.27			
Itching	0.02			
Like a scratch	0			
Like a sting	0.02			
Scratching	0.03			
Stinging	0.05			
Shocking	0.11			
Shooting	0.02			
Splitting	0.02			
Numb	0,16			
Stiff	0.02			
Swollen	0			
Light	0.05			
Awful	-	0.27		
Deadly	-	0		
Dying	-	0.18		
Killing	-	0.27		
Crying	-	0.27		
Frightening	-	0.36		

	Sensory	Affective	Evaluative	Temporal
Screaming	-	0.36		
Terrifying	-	0		
Dizzy	-	0.09		
Sickening	-	0.09		
Suffocating	-	0.45		
Annoying	-	-	0.5	
Bad	-	-	0.25	
Horrible	-	-	0.5	
Miserable	-	-	0.62	
Terrible	-	-	0.25	
Uncomfortable	-	-	1	
Never goes away	-	-	0.75	
Uncontrollable	-	-	0.35	
Always	-	-	-	0.36
Comes and goes	-	-	-	0.27
Comes on all of a sudden	-	-	-	0.45
Constant	-	-	-	0.27
Continues	-	-	-	0.45
Forever	-	-	-	0.27
Off and on	-	-	-	0.18
Once in a while	-	-	-	0.27
Sneaks up	-	-	-	0.18
Sometimes	-	-	-	0.45
Steady	-		-	0.54

Continuously, from the “Evaluative” descriptive pain words, a very surprising change occurs to ‘annoying' description decreasing from f= 0.87 to f= 0.5. Interestingly, the description of the “Temporal” level remains the same, high and more selective from children's vocabulary. Words such as “always, comes out of a sudden, steady, and continues,” have a very high frequency in comparison to all the other groups of descriptive pain words.

3.7. Results from the Pain Coping Questionnaire (PCQ) for both groups after the art intervention

In the last phase of the study design, the administration of the questionnaires occurred when all the children from the experimental group ended the art intervention sessions. Table 23 describes the results from the second questionnaire for both experimental and comparative group after the intervention. As demonstrated below, the results from the experimental group contain many changes. The first scale of “Approach” coping strategies

underwent an increase from M=2.8 to M= 4.1 while from the comparative group, the difference is very small increasing from M= 2.3 to M= 2.7. Interestingly, in the comparative group, the SD is 2, almost the same with the experimental group.

The same proceeds with the second coping scale “Distraction.” The experimental group has a change from M= 3.8 to M= 2.9 and the comparative group from M= 3 to M= 3.4. In regard to the last scale “Emotion-Focused avoidance”, the experimental group underwent a change from M= 1.88 to M= 1.2 and the comparative group from M= 1.7 to M= 2.6. In the last two coping strategies the change is not significant, but is sustainable from comparison. The main two subscales having a deep modification are the “Problem Solving” and “Seeking Social Support” in the experimental group, from M= 2.5 to M= 4.6 and M= 3.3 to M= 4.8 respectively. Differently, happens in the comparative group with a profound change in the ‘externalizing' subscale from M=0.7 to M= 3.16 as well as the “behavioral distraction” from M=2.7 to M=3.8.

For each of the cases in both groups, the three coping scales results appear in Table 23. In the experimental group, for each participant the values of the “Approach” scale increased drastically in comparison to the baseline results, also with the comparative group.

Table 24. Mean and Standard Deviation of PCQ scale/Subscale for both groups after art intervention (N=6)

Children in the experimental group (N=6)			**Children in the comparative group (N=6)**	
Coping Scales	**Mean**	**Standard Deviation**	**Mean**	**Standard Deviation**
Approach	4.1	1.97	2.7	2
Distraction	2.9	1.47	3.4	1.03
Emotion-focused avoidance	1.2	1.63	2.6	1.47
Subscales				
Information seeking	3.6	0.82	2.3	0.81
Problem Solving	4.6	0.51	2.8	0.41
Seeking social support	4.8	0.41	2.5	0.54
Positive self-statement	3.3	1.03	2.5	1.04
Behavioral Distraction	3	0.62	3.8	0.98
Cognitive distraction	2.3	0.51	4	0.89
Externalizing	1.3	1.21	3.16	0.75
Internalizing/Catastrophizing	1	0.63	2.2	0.98

The comparative group on the other side continues to have higher values on ‘Distraction' scale and decrease in the “Approach” scale.

In the first case of Vanessa, having a very low level of pain, and very stable health conditions, her improvements are very clear. In the scale of “Approach,” she has a change from (0.57) to (0.71) choosing more frequently ‘problem solving' and ‘seeking social support' such as "Thinking what needs to be done to make things better," "Focus on the problem and see how I can solve it." The same conclusions go for Alex. Different from Vanessa, he has a higher level of pain, and severe symptoms when they occur. His improvements in the “Approach” scale from (0.37) to (0.75) describe his great collaboration and dedication to the intervention. Again, the two most frequent subscales are “Problem-Solving” and “Seeking Social Support.”

For Patricia, her results in the “Approach” were positive even before the intervention, and they persist to be the same. She had an increase in the ‘externalizing' subscale from (0) to (0.17) frequently selecting "Argue or fight" and "Yell to let off steam." Although the “Distraction” subscale becomes lower, she selected more “Externalizing” behaviors.

Eleonor showed great improvement in the “Approach” scale with a higher frequency of “Seeking Social Support” and “Positive Self-Statement.” The “Emotion-Focused Avoidance” also had lower values from the first implementation. As regarding Ricardo, with a high level of pain, and a dangerous health situation, his results alterations were also dependent upon the last events. The ‘Approach' scale had the highest values but decreased from (0.84) to (0.66) from the first implementation. Interestingly, Ricardo chose frequently as well the ‘internalizing' subscale such as "Worry too much about it," "Think that nothing helps," and "Keep thinking about how much it hurts." At last, Luis had the same values for “Approach” scale with a decrease in the “Distraction” scale from (0.86) to (0.49).

The comparative group had almost the same results, except the ‘Approach' scale going through a decrease. Although it happened differently in the case of Bernardo, there was an increase in the “Approach” from (0.42) to (0.58). Mariana had a high increase in the “Emotion-Focused Avoidance' from (0.1) to (0.42) such as "Get mad and throw or hit something" and "Say mean things to

people." Differently, from Mariana, Pedro had a decrease in the “Internalization” subscale such as "Worry too much about it" and "Think that nothing helps."
Liliana and Cristiano had very different approaches on the “Distraction” scale. Liliana had a change from (0.72) to (0.55), and Cristiano from (0.46) to (0.66). Cristiano also had a high increase in the values of “Internalizing” subscale from (0.3) to (0.25). At last, Carla had almost the same values from the first implementation of the questionnaire, without changing the distribution of the values among the three scales and subscales.

Table 25. Descriptive results for each of the 12 participants individually for the PCQ after the art intervention (N=12)

Experimental group (N=6)	Approach (%)	Distraction (%)	Emotion-focused (%)
Vanessa	0.71	0.44	0.08
Alex	0.75	0.5	0.08
Patricia	0.66	0.5	0.17
Eleonor	0.61	0.55	0.3
Ricardo	0.66	0.38	0.33
Luis	0.63	0.49	0.16
Comparative Group (N=6)	-	-	-
Bernardo	0.58	0.61	0.41
Mariana	0.37	0.55	0.42
Pedro	0.39	0.44	0.58
Liliana	0.36	0.55	0.5
Cristiano	0.37	0.66	0.25
Carla	0.45	0.61	0.5

Table 26 describes more precisely the frequency coping scale/subscale for each group after the art intervention. Starting with the experimental group, compared to the results from the questionnaire implemented before the intervention, children have selected with a higher frequency “Information Seeking” such as “Ask question about the problem”; “Problem Solving” with “Focus on the problem and see how I can solve it,” “Think of different ways to deal with the problem,” “Think about what needs to be done to make things better'; and "Seeking Social Support' "Talk to a friend about how I feel,” “Talk to a family member about how I feel.”
Differently from the first results, now the “Behavioral and Cognitive Distraction” have a lower frequency such as “Forget the whole thing,” “Ignore the situation,” and “Try to forget it.” Although, from the first results the last two subscales had

a lower frequency, and on the repetition of the questionnaires their values appear lower such as ‘keep thinking about how much it hurts.'

Table 26. Frequency of each performed behavior grouped in coping strategies subscales from the PCQ for children in experimental group after the art intervention (N=6)

Items	Factors							
	Information Seeking	Problem Solving	Seeking social support	Positive self-statement	Behavioral distraction	Cognitive distraction	Externalizing	Internalizing /Catastrophizing
Ask question about the problem	3.33							
Ask a nurse or doctor questions	2.28							
Find out more information	3							
Learn more about how my body works	2.83							
Focus on the problem and see how I can solve it	-	3.83						
Think about what needs to be done to make things better	-	3.66						
Think of different ways to deal with the problem	-	2.8						
Figure out what I can do about it	-	2.17						
Try different ways to solve the problem until I find one that works	-	2.67						
Talk to a friend about how I feel	-	-	3.16					
Talk to someone about how I am feeling	-	-	3.16					
Tell someone how I feel	-	-	3.5					
Talk to a family member about how I feel	-	-	3.17					
Let my feelings out to a friend	-	-	3.5					
Tell myself, don’t worry everything will be OK	-	-	-	2.5				
Say to myself, be strong	-	-	-	1.83				
Tell myself it’s not so bad	-	-	-	3.17				
Tell myself I can handle anything that happens	-	-	-	2.66				
Say to myself things will be OK	-	-	-	2.5				
Go and play	-	-	-	-	2			
Do something fun	-	-	-	-	1.67			
Do something I enjoy	-	-	-	-	2			
Do something active	-	-	-	-	1.67			
Do something to take my mind off it	-	-	-	-	1.33			
Forget the whole thing	-	-	-	-	-	1.5		
Ignore the situation	-	-	-	-	-	1.17		
Try to forget it	-	-	-	-	-	1.33		
Put it out of my mind	-	-	-	-	-	1.5		
Don’t thing about it	-	-	-	-	-	1.83		
Say mean things to people	-	-	-	-	-	-	1.33	
Argue or fight	-	-	-	-	-	-	1.67	
Yell to let of steam	-	-	-	-	-	-	1.16	
Get mad and throw or hit something-	-	-	-	-	-	-	1.5	
Curse out loud		-	-	-	-	-	1	
Worry that I will always be in pain	-	-	-	-	-	-	-	1
Keep thinking about how much it hurts	-	-	-	-	-	-	-	1.5
Think that nothing helps	-	-	-	-	-	-	-	1.17
Think that the pain will never stop	-	-	-	-	-	-	-	1.17
Worry too much about it	-	-	-	-	-	-	-	1

Contrary to the experimental group, the comparative group had very small changes in the first scale of coping strategies. Interestingly, from the first scale “Approach” there are very few changes, without containing any difference in the

distributions of the values among the scales as well as the subscales. The drastic changes were spotted in the “Distraction” scale and precisely in the “Cognitive Distraction” subscale. The most frequent replies were "Forget the whole thing" and, "Ignore the situation." In continuity, the last subscale “Internalizing” and “Externalizing” had an increase from the first implementation, precisely in "Try to forget" and "Keep thinking about how much it hurts."

Table 27. Frequency of each performed behavior grouped in coping strategies subscales from the PCQ for the comparative group after the art intervention (N=6)

Items	Factors							
	Information Seeking	Problem Solving	Seeking social support	Positive self-statement	Behavioral distraction	Cognitive distraction	Externalizing	Internalizing /Catastrophizing
Ask question about the problem	1.5							
Ask a nurse or doctor questions	2							
Find out more information	1.83							
Learn more about how my body works	1.67							
Focus on the problem and see how I can solve it	-	2						
Think about what needs to be done to make things better	-	1.83						
Think of different ways to deal with the problem	-	2						
Figure out what I can do about it	-	2						
Try different ways to solve the problem until I find one that works	-	1.5						
Talk to a friend about how I feel	-	-	1.83					
Talk to someone about how I am feeling	-	-	1.83					
Tell someone how I feel	-	-	1.33					
Talk to a family member about how I feel	-	-	1.67					
Let my feelings out to a friend	-	-	1.83					
Tell myself, don’t worry everything will be OK	-	-	-	2.16				
Say to myself, be strong	-	-	-	1.83				
Tell myself it’s not so bad	-	-	-	1.5				
Tell myself I can handle anything that happens	-	-	-	1.33				
Say to myself things will be OK	-	-	-	1.5				
Go and play	-	-	-	-	2.66			
Do something fun	-	-	-	-	2.16			
Do something I enjoy	-	-	-	-	2.67			
Do something active	-	-	-	-	2.5			
Do something to take my mind off it	-	-	-	-	2.17			
Forget the whole thing	-	-	-	-	-	2.66		
Ignore the situation	-	-	-	-	-	3.17		
Try to forget it	-	-	-	-	-	2.67		
Put it out of my mind	-	-	-	-	-	2.33		
Don’t thing about it	-	-	-	-	-	2.17		
Say mean things to people	-	-	-	-	-	-	2.16	
Argue or fight	-	-	-	-	-	-	2.66	
Yell to let of steam	-	-	-	-	-	-	2.33	
Get mad and throw or hit something-	-	-	-	-	-	-	1.83	
Curse out loud		-	-	-	-	-	2.17	
Worry that I will always be in pain	-	-	-	-	-	-	-	2.5
Keep thinking about how much it hurts	-	-	-	-	-	-	-	2.67
Think that nothing helps	-	-	-	-	-	-	-	1.33
Think that the pain will never stop	-	-	-	-	-	-	-	1.17
Worry too much about it	-	-	-	-	-	-	-	2

In Table 28, are shown the results of the PCQ and APPT correlation. As described from the table below the “Information Seeking” subscale, the experimental group has a higher frequency when the pain is sensory, affective and evaluative. Differently, the comparative group has a negative correlation with the sensory pain. Although, in both cases, the participant concluded that they ask less information when the pain is temporal.

“Problem-Solving” on the other hand for both groups has a positive correlation with ‘sensory' and ‘affective' pain. The participants believe that the more they are aware of their pain, or differently described as the more the pain affects their daily life, the more they are prompt to ask for a solution to their problem. The experimental group concluded that the more ‘sensory' and ‘evaluative' the pain is, the more they use “Positive Self-Statement.” The comparative group, stated exactly the contrary, using less “Positive Self-Statement” when the pain is ‘sensory' and ‘evaluative' (Table 28).

As described from the table 28 below the “Information Seeking” subscale, the experimental group has a higher frequency when the pain is ‘sensory’, ‘affective’ and ‘evaluative.’ Differently, the comparative group has a negative correlation with the sensory pain. Although, in both cases, the participant concluded that they ask less information when the pain is temporal.

“Problem-Solving” on the other hand for both groups has a positive correlation with ‘sensory' and ‘affective' pain. The participants believe that the more they are aware of their pain, or differently described as the more the pain affects their daily life, the more they are prompt to ask for a solution to their problem. The experimental group concluded that the more ‘sensory' and ‘evaluative' the pain is, the more they use ‘positive self-statement.' The comparative group, stated exactly the contrary, using less “Positive Self-Statement' when the pain is ‘sensory' and ‘evaluative' (Table 28).

In continuity, ‘behavioral distraction' subscale for both groups has a negative correlation with the ‘affective' pain, differently translated, the higher the level of impact pain leaves on their personal lives, the less their need to ask for distraction or outer stimulus. Although the comparative group has a high value

for the combination of ‘temporal' pain and the ‘behavioral distraction,' emerging behavioral attempt to overpass the temporal symptoms.

Table 28. Descriptive correlation between coping subscales (PCQ) and the pain scales (APPT) for both groups after the art intervention (N=6)

Coping/Pain	Experimental group				Comparative group				
	Sensory	Affective	Evaluative	Temporal	Sensory	Affective	Evaluative	Temporal	P value
Information seeking	0.61	0.63	0.59	-0.38	-0.14	0.18	0.81	-0.11	0.02
Problem Solving	0.11	0.75	0.66	-0.61	0.55	0.37	-0.35	0.11	0
Seeking social support	0.2	-0.31	-0.83	0.61	0.37	0	0.11	-0.24	0.01
Positive self-statement	0.21	0.12	0.66	-0.35	-0.64	-0.54	-0.65	0.63	0.19
Behavioral Distraction	0.08	-0.61	-0.23	0.64	0.51	-0.08	0.23	-0.76	0.11
Cognitive distraction	0.11	0.75	0.75	-0.96	-0.15	0	-0.56	0.3	0.02
Externalizing	0.23	-0.21	-0.28	0.03	-0.39	-0.05	0.02	0.29	0.01
Internalizing/Catastrophizing	0.44	0.41	-0.69	0.64	-0.64	-0.05	0.14	-0.04	0.03

*Significance difference ($P < 0.05$)

Regarding the ‘cognitive distraction' in the experimental group, it gets lower when the pain is more ‘temporal,' different from the comparative group. Interestingly, the “Externalizing” subscale in the experimental group decreases when the child has a lower ‘evaluative' pain, while the comparative group has a positive correlation with the ‘temporal' pain. In conclusion, “Internalizing” subscale again has an inverse coefficient for both groups especially when the pain is more ‘sensory.' Respectfully, for the experimental group, there is a positive correlation between the self-awareness to classify pain with internalizing behaviors, while, in the comparative group the correlation is negative, internalizing less when having more self-awareness about their pain and physical conditions.

The tables below (29,30) describe the correlation between age and gender, and the coping strategies from the PCQ questionnaire after the art intervention. Once again the difference between boys and girls in both groups remain the same even after the art intervention. Interestingly there is a negative correlation between the “Distraction” coping scale and the age for both groups. In both cases, with the passing of ages such as the case of Vanessa, Bernardo, and Luis, use less distraction strategies to deal with a stressful situation.

Table 29: Descriptive correlation of coping scales/subscales and age in both groups after the art intervention (N=6)

Coping scales	Age Experimental group	Age comparative group
Approach	0.36	0.47
Distraction	-0.69	-0.21
Emotion-focused	-0.23	0.02
Coping Subscales		
Information seeking	0.4	0.73
Problem Solving	0.27	0.09
Seeking social support	0.7	0.31
Positive self-statement	-0.43	0.16
Behavioral Distraction	-0.67	-0.07
Cognitive distraction	0.31	-0.43
Externalizing	-0.62	0.62
Internalizing/Catastrophizing	0.67	-0.43

Table 30: Mean and Standard Deviation for each scales/subscales of the coping PCQ questionnaire related to gender for both groups after the art intervention (N=6)

	Children part of art intervention (N=6) *Male N=3* *Female N=3*		**Children not part of the art intervention (N=6)** *Male N=3* *Female N=3*	
Coping Scales	**Mean**	**Standard Deviation**	**Mean**	**Standard Deviation**
Approach				
Male	4.2	1.15	1.3	2.88
Female	4.1	0.57	1.2	1.57
Distraction				
Male	2.8	1.15	1.72	2.08
Female	3	1	1.72	0.57
Emotion-focused avoidance				
Male	1.2	1.52	1.25	2
Female	1.2	1.52	1.4	0.57
Subscales				
Information seeking				
Male	4	0	2.67	1.15
Female	3.3	1.15	2	0
Problem Solving				
Male	4.7	0.58	3	0
Female	4.6	0.57	2.6	0.57
Seeking social support				
Male	5	0	2.3	0.57
Female	4.6	0.57	2.7	0.57
Positive self-statement				
Male	3	1	2.7	1.15
Female	3.7	1.15	2.3	1.15
Behavioral Distraction				
Male	2.7	0.58	3.7	1.15
Female	3.3	0.57	4	1
Cognitive distraction				
Male	2.6	0.57	4	1
Female	2	0	4	1
Externalizing				
Male	1	1	3.3	1.15
Female	1.6	1.52	3	0
Internalizing/Catastrophizing				
Male	1.3	0.57	1.6	1.15
Female	0.6	0.58	2.6	0.57

3.8. Results from the KidCope questionnaire for both groups after the art intervention

The third questionnaire measures the three scales of coping mechanisms as the PCQ, utilizing different approaches, and questions. The results from the 11 subscales support the same conclusions as the results from the first questionnaire. The frequency and the efficacy of the coping strategies was measures together as a set of one. Specifically, “Distraction” for the experimental group had a decrease in mean from M=3.5 to M=1.8, highlighting as well the confirmation from the PCQ, as opposed to the comparative group with an increase in mean from M=2.3 to M=3.6. More specifically, the values of Min/Max confirm the highest frequency of distractive behaviors as opposed to the lowest ones. In the case of ‘distraction' subscale, Eleonor reached the highest frequency replying to "I just tried forgetting it" and "I did something like watch TV or played a game to get over it." From the comparative group, “Distraction” continued to be higher surpassing the one on the first implementation of the questionnaire. The highest value was captured in the case of Pedro, while, Carla was the only one having a frequency of 0 for distractive behaviors.

Interestingly the “Wishful Thinking” subscale didn’t change in both groups, reaching a higher frequency in the case of Eleonor in the experimental group and Liliana in the comparative group such as "I wished I could make things different" and "I wished the problem never occurred." Regarding the “Social Withdrawal,” it remained lower in the case of the experimental group but very high for the comparative group with a change mean from M=1.8 to M= 3.6 (Table 32). The highest frequency was encountered in the cases of Bernardo, Mariana, and Liliana selecting "I stayed by myself" and "I didn't talk about the problem."

“Problem-Solving” subscale had a higher increase in the experimental group with a mean from M= 2.3 to M= 4.6. The same happened with the comparative group, although with a lower difference from M=1.7 to M=2.6. The higher frequency was captured in the case of Ricardo for the experimental group and Mariana in the comparative group. Regarding “Internalizing” scale in both

groups, as described in the PCQ results, the same happens in KidCope. For Alex in the experimental group and Bernardo in the comparative group, “Internalizing” had a higher frequency in comparison with the other participants in their respective groups. “Social Support” subscale increased values in the experimental group with the higher frequency of f=3 in all the cases except Eleonor with the lowest frequency of f=1. As about the comparative group, the value remained the same with the higher frequency in the case of Carla. The opposite situation happened in the subscale of ‘resignation' where it had an increase for the comparative group in the case of Carla "I didn't do anything because the problem could not be fixed," while in the experimental group again Eleonor had the highest frequency of the coping subscale.

Table 31. Mean and Standard Deviation for the coping subscales from the KidCope questionnaire for both groups after the art intervention (N=6)

	Experiment group			Comparative group		
Kidcope Subscales	Mean	Standard Deviation	Min/max	Mean	Standard Deviation	Min/max
Distraction	1.8	1.61	0/4	3.6	2.06	0/6
Social withdrawal	1,7	1.63	0/4	3.6	1.75	1/5
Wishful thinking	3.1	0.41	3/4	2.6	1.86	0/5
Self-criticism	0.7	0.81	0/2	0.8	0.75	0/2
Blame others	0.5	0.54	0/1	0.5	0.54	0/1
Problem solving	4.6	1.03	3/6	2.6	0.81	2/4
Internalized emotions	1.3	0.81	0/2	1.6	1.21	0/3
Externalized emotion	0.3	0.31	0/1	0.8	0.75	0/2
Cognitive restriction	2.6	0.51	2/3	1.3	0.83	0/2
Social Support	2.6	0.81	1/3	0.6	0.81	0/2
Resignation	0.6	1.46	0/2	0.6	0.81	0/2

The new results of coping subscales and the three emotional reactions ‘sadness,' ‘anxiety' and ‘anger' gave very different correlation after the art intervention (Table 33). From the beginning, the “Distraction” subscale had a high positive correlation with ‘sadness' and ‘anger' in the experimental group, which is differently interpreted as the higher the level of distractive behaviors the greater the sadness and anger. In the comparative group, interestingly, the sadness has a negative correlation with “Distraction,” whereas both groups has a positive correlation with ‘anxiety' and ‘anger.'

“Social Withdrawal” for the experimental group has a positive correlation, contrary to the comparative group, whereas for both groups the higher the level of social withdrawal the higher the level of anger as well. It happens differently with “Self-Criticism,” promoting a negative relation with ‘anxiety,’

keeping everything inside and blaming oneself thereby making them more anxious. Two different perceptions of the group happen for the ‘blame others' subscale. The experimental group believes that the more they blame others, the sadder they feel, while, the comparative group lean on the negative connection with anxiety, helping them not to feel the anxiety as would feel the need to blame oneself.

Table 32. Descriptive correlation between the coping subscale from KidCope and the emotional classifications for both groups (N=6)

Kidcope Subscales	Correlation variables 1 group			Correlation Variable 2 group		
	Sadness	Anxiety	Anger	Sadness	Anxiety	Anger
Distraction	0.71	0.07	0.62	-0.17	0.31	0.5
Social withdrawal	0.35	-0.14	0.17	-0.21	0.58	0.36
Wishful thinking	0.2	-0.29	0.06	-0.19	0.76	0.55
Self-criticism	0.1	-0.29	-0.06	0.24	-0.34	0.17
Blame others	0.44	0.63	0.47	1	-0.71	0
Problem solving	-0.15	0.23	-0.05	0	-0.15	-0.15
Internalized emotions	0.5	0.29	0.49	-0.30	0.21	-0.42
Externalized emotion	0.79	0.46	0.77	-0.24	-0.34	0.17
Cognitive restriction	0.15	0.46	0.22	0.44	-0.31	-0.31
Social Support	-0.2	0.29	-0.06	0.80	-0.63	-0.15
Resignation	0.1	-0.58	-0.06	0.83	-0.63	-0.15

The ‘problem solving' has an inverse reaction to anger, leaving the participant less angry when they deal or face the problem. ‘Internalizing emotions' also has a different trend in both groups. The experimental group concludes that internalizing emotions increases their anger level, contrary to the comparative group, approving that the internalizing emotions relieve them from anger. ‘Externalizing emotions' on the other side for both group liberates as well, the anger hidden inside, giving a positive correlation.

The other subscale of “Distraction,” has the positive correlation with sadness. The higher the level of cognitive restriction the higher as well, the level of depression. “Social Support” and “Resignation" have a respectively negative correlation with anger and anxiety. The level of anger increases when you lack social support and feel alone, without a way to deal with the problem, while resignation decreases anxiety as a temporary solution, not thinking and dealing with the immediate problem.

CHAPTER 4

DISCUSSION

4. DISCUSSION

The purpose of this exploratory intervention study was to provide an investigation, which examined the use of art therapy techniques with children coping with a chronic disease. Additionally, the research implemented for the first time the art therapy technique in a public hospital in Lisbon, Portugal. The children's involvement in every session was a crucial indicator to evaluate the effectiveness of the intervention. The children in the experimental group from the first session demonstrated their readiness to get involved in the drawing procedure but also to trust someone and share their happiness, fears, and insecurities.

4.1. Coping strategies in relation to pain before the art intervention for both groups

The results from the first two questionnaires include family and friends as two main sources of support when facing difficulties. Mathews, McGrath & Pigeon (1993) claimed that family is a powerful means of socialization with respect to pain. The outcomes fulfilled the conclusions of the theories, especially regarding the family composition and harmony. Such was the case of Ricardo. His family was very conscious of his pain, mainly because of his bone deformation. Ricardo ranked his pain as high level. Thus, while describing the pain distribution over the body it was higher compared to that of the other children. The child's actual experience of pain is modified by the context in which the pain is evoked and does not necessarily relate to the actual intensity of pain (Carter, 1994); it includes cognitive, experiential, social, behavioral, emotional, physical, and contextual components (Gillies, 1995). All these factors play a part in the child's eventual understanding of pain, and his/her ability to cope with it. Nevertheless, based on his pain perceptive ranking, the words he selected were "annoyed," "pulping," "like a shock," "numb," "uncontrollable," "comes out of a sudden," describing mainly a temporary pain. Different from Patricia classifying a high level of pain but using "horrible," "pressure," "hot,"

"miserable," "sometimes," and "comes out of a sudden," to refer to pain. Her ranking was also a temporary pain. In the cases of Bernardo and Christiano from the comparative group, both selecting a high level of pain and describing it as "horrible," "suffocating," "terrifying," and "Once in a while" for Christiano and "scratching," "bad," and "aching" for Bernard. Personal factors such as understanding the source of pain, how to behave, and how you feel, affect pain perception. Thus, pain can be modified by a variety of factors (McGrath, 1994). Regarding the case of Mariana with a medium level of pain, is a more "evaluative" type of pain, which refers better to their high sensitivity to perceive the pain or better evaluate the pain by introducing references such as "annoyed," "uncomfortable," "terrible," "uncontrollable," etc.

Another one having temporal pain was Vanessa, with a medium level of pain using descriptive words such as "annoyed', "sensitive," "numb," and "steady." The temporal level of pain is a sudden experience of pain, not continuous, but its intensity varies depending on the chronic disease. Unlike adults, children have a rapidly changing frame of reference as they mature and sustain more diverse types of pain sensitivity. They describe their pain not only according to its hurting aspects but also to its sensory attributes, such as the quality, intensity, duration, location, frequency, and unpleasantness that is experienced (Paiget & Inhelder, 1969). Children learn specific words to describe the various aspects of all their perceptions, words to denote different sounds, colors, and tastes. For the cases of Vanessa and Bernardo, who are older then the rest of the participants, it's easier describing accurately the pain. The development literature shows that coping styles progress as children age (Donaldson et. al. 2000). They found that young children used a narrower range of coping behaviors than did adolescents. As children grow into adolescence, they use a wider range of coping responses, and vary their coping across situations (Brown et.al. 1986; Compas et.al., 1988; Tyc et.al., 1995).

Such is it for Christiano, Liliana, and Carla with a temporal level of pain. In the case of Alex, the level of pain is high as his blood cells get stuck in small vessels depriving his body from getting the necessary oxygen. Girls are more inclined to turn to others, think hopefully, and resort to tension-releasing

strategies, and they are more likely to do this as they get older (Frydenberg & Lewis, 2000), whereas boys tend to avoid the problem or engage in blaming (Hamid, Yue, & Leung, 2003). Reason why Alex refers to pain as "annoying", "killing", "numb", "uncontrollable", "pressure", and "forever". The descriptive pain scale is "effective," reasonably, for affecting his life continuously and being always present.

Different from Alex, Eleonor also has a high level of pain but it's mainly "Sensory" reason why she describes it as "unhappy", "terrible", "pinching", "hot", and "pressure". Although, Eleonor being a very shy girl, surprised her parents a lot with this level of pain perceptions, as they always believed the medication was keeping the pain under control. Emotional factors such as elevated anxiety, distress, anger, and low mood, can increase the child's pain perception (McGarth, 1994) and render subsequent medical procedures and pain management more difficult (Frank et.al., 1995). In this context, she has a positive family model, masking her perceptions to the nurses or pediatricians, but as an introvert, the family despite the positive model needs other means to achieve the equilibrium. A positive family member also brings less stress and anxiety to the children (Kliewer & Lewis, 1995).

Considering the positive family model, Ricardo has a very caring and protective family, always present; calling Ricardo at all times to ensure he is fine, reasons why he has a very small difference between the "Approach" (84%) and "Distractive" (87%) scales of coping. Although, distractive behaviors contain the majority of his answers, such as "Ask questions about the problem," "Think about what needs to be done to make things better," and "Tell me it is not that bad." But most of the questions and the higher frequency of performing are included in the "Distraction" scale, mainly "behavioral distractions" such as "Do something fun", "Do something I enjoy" and the "cognitive distractions answers" are: "Try to forget it," and "don't think about it." As a result, from the general result of the group, when the pain perception is "temporal" there are higher chances the children will seek for active coping strategies such as "problem-solving" or "seek social support" and lower chances for "externalizing" and "internalizing." Based also on Varni et.al. (1996) the pain intensity is directly related to active coping strategies. The lower the pain level, the higher the

chances to ask for support, self-efficacy, etc. Such are the cases of Cristiano and Mariana from the comparative group having higher approach scale scores compared to the distraction scale.

The same conditions are captured in Patricia's case. Her model family and the relation with her father help her to provide effective alternatives to cope with the situation. Although, the longer it continues, with the passing of time, like Ricardo, quiet small difference, almost not significant between "approach" (0.57%) and "distraction" (0.66%), will start to get deeper. Her higher ranking replies among the "approach" scale came from the "seeking social support" such as "Tell a family member how I feel," "Tell someone how I feel." "Distractive" behaviors include the majority of her replies and the higher frequency of performing such as "Put it out of my mind," "Don't think about it," "Tell myself it's not so bad," and "Do something to take my mind off it." The same conclusion is applicable to Patricia, as the pain is Temporal; the chances to ask for help and seek support are higher, compared to the others. Nevertheless, there are other factors involved such as contextual, emotional, social, and academic, but those are not involved as a part of the direct relation with pain and coping strategies.

Anyways, some of them for a detailed analysis can be useful, especially in the case of Eleonor, who is very shy and a social introvert. These personal characteristics also make the difference with Alex, who also has a high level of pain. Eleonor's pain is mainly sensory, but that doesn't make any difference or any higher/lesser important from the effective perception of pain in the case of Alex. Eleonor has a profound difference between "approach" and “distractive” scales corresponding (36%) with (73%). Her main answers and high frequency coping strategies were “behavioral distraction” such as “Go to play”, “Do something to take my mind off”, “Cognitive distraction such as “Forget the whole thing”, “Ignore the situation”, and “internalizing” such as “Keep thinking about how much it hurts”, and “Think the pain will never stop”. Varni et. al., (1996) also mentions the positive correlation between catastrophizing (internalizing) with a higher level of pain. Also, the sensory perception of pain that she manifests is a direct response to being focused on the feelings and body perceptions to describe better the details of the pain rather than the other characteristics.

Alex, for instance, has mainly distractive strategies at 54%. Also, his family situation and maybe even social interaction has problems, reason why he likes to be alone and not talk to anybody. Most frequent strategies are cognitive distractions such as "Forget the whole thing," "Put it out of my mind," "Don't think about it" and internalizing such as "Think that nothing helps" "Keep thinking how much it hurts." From the conclusions of Wallander et.al. (1989), behavioral problems when dealing with physical conditions increase the chances to internalize and social withdrawal.

Luis and Vanessa have a lower level of pain, and that is also shown in the result at the perceptive pain level and the words they use. Nevertheless, there is a slice difference between them as in the case of Luis, being younger, despite the family problems, he still has two women taking care of him, and giving him a family. The reason why the difference between "approach" scale and "distractive scale" is not big is (74%) and (82%). The coping strategies selected by him approaches mainly the "problem solving" subscale such as "Think of different ways to deal with the problem", "Figure out what I can do about it", and "seeking social support" subscale such as "Talk to a friend about how I feel", and "Tell a friend how I feel". Edgar and Skinner (2003) argue that people may use both avoidant and approach coping strategies in managing a single situation, or that some specific behaviors may function in both categories depending on the context. Vanessa, instead, especially regarding her teen age and her overprotective mother, although more like a bodyguard controlling her moves, regarding the pain she selects "internalization" subscale such as "Think that nothing helps," and "Worry too much about it." Some authors suggest that problem-focused coping is more adaptive for controllable circumstances, but that emotion-focused is actually more appropriate for uncontrollable circumstances in which people cannot enact change in the environment, only within themselves (Altshuler & Ruble, 1989; Compas et.al., 1991; Donaldson et.al., 2000; Stallards et.al., 2001).

4.2. Coping strategies related to intensity of stress response before the art intervention

Regarding the two variables of coping strategy and stress response, both of them are part of the KidCope test. Different from the first test, KidCope reflects the coping strategies children think, not only related to pain, but to a stressful situation related to their health condition and effectiveness of this coping strategy after using it.

In the case of Patricia she selected “Social withdrawal”, “wishful thinking” and “internalizing” subscales such as “I stayed by myself “, “I wished I could make things different", "I tried to calm myself down", and indicated that these strategies were very helpful although with a high level of sadness and anxiety. Patricia, at the beginning of the test picked as a stressful event, when she is at the hospital without her father, and undergoing all the medical procedures alone. Varni et.al. (1996) defines social withdrawal as a strategy selected by people with high level of pain and a high level of anxiety (from the KidCope reults). All of these criterions are part of Patricia's cases. Two most extreme circumstances for "Wishful thinking" are Bernardo and Pedro from the comparative group replying with high frequency "Wished the problem never happened," and "Wished things were different."

With almost the same results but using more distracting activities such as "I did something like TV or playing games," made Luis to have a lower level of anxiety. Again, referring to Varni et.al. (1996) behavioral strategies such as distraction, in this case, are part of the lower levels of pain. For Luis, pain is very low, and also distraction makes the anxiety coming from wishful thinking and social withdrawal less stimulant.

Different from the other test, Ricardo performed "Distractive" behaviors and "internalizing emotions, and to his perceptions, they were very helpful although with a high level of anxiety. Higher levels of coping and greater numbers of coping strategies have been associated with more distress and higher levels of anxiety and depression (Curry & Russ, 1985; Spirito et.al., 1994; Stallard et.al., 2001; Vernberg et.al., 1996).

Distracting and keeping the emotions or thoughts inside doesn't chase the problem away, just represses it to come up at any time during the day, which increases anxiety at the moment of facing the problem. Such as Carla in the comparative group frequently doing "Tried to forget," and "Tried to do something else like watch TV or play games."

The same results are the conclusions from Vanessa and Eleonor, despite their differences of pain level. They both choose distraction. Vanessa is more focused on "wishful thinking" and "resignation" such as "I didn't do anything as the problem couldn't be fixed" to help her, but still with a high level of sadness and anxiety.

A little differently, Eleonor and Pedro select “social withdrawal” to help deal with the stressful situation, but anxiety has higher levels according to Varni et.al (1996) that higher levels of pain such as the conditions of Eleonor correspond with social withdrawal and high level of anxiety. Miller et. al. (2000) postulated that the high occurrence of wishful thinking in children might account for by children’s imaginative cognitions. However, Vernberg et.al. (1996) found that although wishful thinking was frequently used, it did not have a distinctive effect on adjustment. Liliana and Carla selected Resignation scale, frequently resulting in high level of anxiety and sadness.

Alex instead, different from the others, has also a higher level of anger brought on by three coping strategies such as distractive, social withdrawal, wishful thinking. Social withdrawal and blaming others are two maladaptive coping responses that seem to be particularly determent to children’s adjustment after experiencing a major stress (Spirito et.al., 1994; Stallard et.al., 2001). Van der Bree et. al. (1990) concluded that avoidance came as a result of high level of pain and infused with sadness when having a long duration of pain.

4.3. Coping strategies revision in relation with pain after the art intervention for both groups

All data accumulated, including questionnaire findings, literature in the field, art intervention sessions, and themes that emerged, was used to assess the

potential benefits of providing art intervention to children with a chronic disease. Research examining children's coping behavior has found coping behavior to be fairly stable, remaining consistent across various situations (Donaldson et.al. 2000; Spirito et.al. 1994, Stallard et.al. 2001). Donaldson et.al. (2000) found that although children's coping strategies fluctuated slightly across situations overall pattern remained constant. In fact, some researchers suggest that children coping behavior is more consistent and stable than that of adults (Compas, Malcarne, & Fondacaro, 1988). However, few intervention studies followed to discover that art can in fact make a change in the children's behavious and modulate the coping strategies children use to face a stressful situation (Favara-Scacco et.al., 2001; Baider, 1989; Frick, 1987; Ball, 2002). Self-reported pain assessment results contradicted parental perception regarding the sensory experience of the disease. Although, Kashani et. al., (1992) and Lavigne & Faire-Routman (1992) warned future researchers to evaluate parents and children's report, due to inconsistent results.

After seven sessions of art intervention with the children in the experiment group, both groups underwent the third phase of the study, re-administering the three instruments APPT, PCQ, and KidCope. The art intervention kept the children from the experimental groups refreshed on the concepts such as pain, coping, and strategies, while, the other group had very few memory about the terminology and took a longer time to reply to each of the questionnaires.

The first administered questionnaire was the APPT, presenting the measurement of pain. Interestingly, Ricardo was more aware and direct about his pain situation. From the first implementation, he considered his pain to be high level, and on the second attempt he described it high as well but becoming more aware of his pain description. His medical history over the past months made him more aware of his real situation and is the reason why his pain perception now has a sensory description such as 'horrible, killing, uncomfortable, hurts, make cry, and sickening.' The pain perception became more present and stable while on the first try he described it as more temporal. A long duration of illness and pain lowers the intensity of perception (Schowalter, 1993) and the legitimate response is resignation or acceptance of

your continuing situation as such. As such, when you expect the same perception you attribute less pain (Beecher, 1959). Although, the change of his actual health conditions, the severity of the symptoms, shaking hands, losing equilibrium, feeling of dizziness, took him to an unknown level of perception, requiring an increase in the routine pain (McMurtry el.al., 2015; Taddio et.al., 2009).

Different in the case of Patricia, the perception of high level of pain while changing on the second administration of the APPT from ‘temporal' emotional perception to more ‘evaluative.' Her emotional descriptions are ‘horrible, unhappy, like an ache' although, ‘temporal' description persists with ‘always present, comes all of a sudden, sometimes.' Patricia describes the pain as more temporal but intense and uncontrollable for her. As such, her control over the symptoms remains low, as their appearance is very unpredictable, leaving her more open to emotional uncertainty (Ebata & Moos, 1991). Continuing with another high perception of pain, in the case of Alex, who describes it as ‘annoying, unhappy, uncomfortable, uncontrollable, and never goes away.' His emotional description passed from more ‘affective' to more ‘evaluative,' also after the attempt to be more open and collaborative about his health conditions, he is more aware to describe them as such. Despite his self-awareness to evaluate the pain, he continues to describe it as having a significant impact on his everyday life using ‘numb, suffocative, screaming, crying, and killing'.

From the comparative group, Bernardo continues to perceive a high level of pain although now he is more self-aware of it in comparison with ‘sensory' from the first administration of the APPT. He describes it as ‘horrible, terrible, bad, uncontrollable, and suffocative.' Interestingly, in the case of Cristiano, perceiving a high level of pain, in both administering questionnaires he describes his pain as more ‘temporal' using ‘comes out of the sudden, comes and goes, constant, continues' although, he is aware to describe his pain from the ‘sensory' description using ‘sensitive, pressure, pinching, biting'. Experiencing the same level of pain over a long duration of time has given him more time to lower the border of sensitivity (Schowalter, 1993).

The cases of the medium level of pain, according to Luis, Vanessa, and Eleonor from the experiment group evaluated their pain more ‘temporal' using ‘Always, sometimes, forever, comes out of a sudden, once in a while, on and off.' Respectively, Luis describes his pain as being more ‘annoying, unhappy' but was more self-aware describing his ‘sensory' emotions toward the perceptions such as ‘sore, burn, pressure, biting, itching, pounding.' While for Vanessa, with a lower level of pain than Luis, becomes more ‘sensory' increasing her ability to precisely describe her symptoms as ‘sensitive and pressure.'

Different, in the case of Eleonor, on her first description of pain, she used many ‘sensory' and ‘affective' descriptions, on her second administering of APPT, she focused more on the ‘temporal' description. Eleonor increased her control over the pain (Compas, Malcarne, Fondacaro, 1988), and became more predictive toward the medical care at the hospital (Pate et.al., 1996).

From the comparative group, Carla is another participant with a high perception of pain, although on her second administration of APPT she describes pain as more ‘temporal' such as ‘comes out of a sudden, on and off, constant' in comparison with the first time ‘evaluative' that she simply mentions as ‘uncomfortable' gaining such an immunity to chronic symptoms over time (Schowalter, 1993).

Passing now on the three remaining medium level pain perception from the comparative group, with the cases of Liliana, Mariana, and Pedro. All the three cases share their ‘temporal' description of pain that prevail the same even on the second administration of the APPT. Liliana, for instance, also describes her pain ‘sensory' using ‘sensitive, hot, pressure, burning, scratching, swollen,' while Pedro uses more ‘soar, hot, numb.' Lastly, Mariana describes the pain as ‘temporal' and ‘evaluative' using words such as ‘annoying, uncontrollable, and uncomfortable.'

Knowing that their pain perception had almost the same perceptions from the first administration of APPT, with very little changes in their word pain description, also gave room to compare the results from the PCQ questionnaire administered after the art intervention. The results showed an interesting change in the experiment group. Ricardo compared to all the other participant

had a higher level of pain, as well as his unstable health situation in the last month, unbalanced a little the relation with his family and trust in the medical intervention. Although, ‘approach' scale of coping or problem-focused coping is higher especially for the ‘problem solving' and ‘positive self-statement,' Ricardo, differently this time, started to internalize and hide his sadness as well as the somatic complaints (Lavigne & Faier-Routman, 1992). His family support has given him an enormous motivation to distract him from the problem, but at the same time, their need not to face the problem, but hide it, harmed him, believing that something that he could not control was coming. Ricardo started to Catastrophize more, when the pain became higher and unstable, unable to predict anymore what his new routine will be (Varni et al. 1996). Brown et.al. (1986) found that children who catastrophize tend to display higher rates of anxiety.

Differently, Patricia during the seven sessions of intervention realized that her father was getting closer to her father, used pain as a mean to attract his attention. However, this freedom gave her time to build social connection with her classmates. Unable to create this detachment from her father immediately, she started to externalize "argue or fight', ‘yell to let out steam.' Despite her high level of pain she still became very aware of her situation to seek for information and find various ways to resolve the problem. Instead, in the case of Eleonor, she found her mother as the barrier of her insecurities and health situations. The active connection and the trust in her mother gave her some detachment from the imaginary friend.

Alex had the best improvements, especially because for the first time he trusted the educators, nurses and other patients in the waiting room at the hospital. His artistic talent was a big motivation to his improvement in trusting other people, and especially confronting his mother. The family situation helped to create a better environment and increase confidence in a person’s abilities (Kliewer & Lewis, 1995). While Vanessa used the sessions as an intervention for her future, she accepted her actual family situation, finding ways to adapt to them, and at the same time fighting for a better solution. The most important strategy was ‘seeking social support, ' and Vanessa used the sessions as well as the

pastor at the church to find freedom understandably for her parents' level of education and perception. Skinner & Zimmer-Gembeck (2007) in a literature review noted that cognitive coping strategies begin to appear in middle childhood. As children progress to adolescence, they are able to use more complex, meta-cognitive coping strategies. For example thet are able to take into account the effect of their coping on themselves and others. Her ‘problem solving' skills became very important for her ‘happiness, presumably as age helps to understand the situation better and become independent (Skinner et. al., 2003).

Eleonor was one of the most complicated cases, living in an imaginary world, willing to have friends but repressing this need by convincing herself that she was better alone. Surprisingly, Eleonor started to externalize her emotions and feelings, which contributed to building an action to regulate the stress (Skinner et. al., 2003), as an attempt to finally reach a connection with the real world that is not imaginary anymore. Her mother became the bridge of her first attempt to express her disease perception, and the peak was her attempt to approach her friends at school, chatting, even though for a short time.

While for the case of Luis, there was an evident decrease of distracting behaviors. His family situation complicated as it is, pushed him to daydream and be a grownup man and take care of his mother. For the first time in the sessions, he was not ashamed to share his weakness and discuss the difficulties at home and the unclear connection with his father. The ‘approach' scale didn't change a lot, but his behaviors to find a way to play football, gave him hope to be a 12-year-old boy again and enjoy that moment of life.

Contrary to the experimental group, the comparative group didn't undergo any art intervention session. Bernardo found more emotion-focused coping behaviors to adapt to his situation while his level of pain were high, and this time was more aware of his ‘sensory' perception. Emotion-focused or avoidant coping has been associated with more distress (Blount et.al., 2005; Spirito et.al., 1994; Tyc et.al., 1995). It is easier to find externalizing/internalizing when dealing with a higher level of pain for children with a chronic disease, as an immediate response toward the health condition (Ebata & Moos, 1991).

Mariana, for instance, continued with the distractive behaviors but this time externalizing more. Her pain level is medium, although, her family and school situation remain unknown, but produces a reaction to "fight and argue" in order to deal with the situation.

Pedro on the other hand feels more comfortable with cognitive distraction and also with internalizing; both reactions to a higher level of pain (Bennet-Branson & Craig, 1997). Liliana uses more behavioral distraction, as a reaction to a lower level of pain as well (Bennet-Branson & Craig, 1997). Cristiano and Carla had almost the same results respectively; for Cristiano it was easier to internalize. He was the first participant in the comparative group to have a higher level in ‘approach' scale of coping from the first administration. That result was reversed in the second administration of the PCQ, offering more point to behavioral distraction. Carla on the other hand doesn't experience any drastic changes. Moreover, the ‘approach' and ‘emotional-focused coping' is the same with the first administration of PCQ.

4.4. Coping strategies related to intensity of stress response after the art intervention

The results from the KidCope questionnaire outcomes had the same conclusions in the PCQ for both groups. More specifically in the experimental group, Patricia shows a higher level of anxiety when trying to find the problem, because facing the problem increases the fear that soon she will hear a bad news (Varni et.al., 1996). Coping efforts are influenced by expectations of future outcomes (Carver et.al. 2009). Patricia has the support of her father and as such, she seeks for social support bringing a positive effect to facilitate cognitive restructuring and orient toward a social networking (Vollrath, 2001) as is her need to make friends at school.

Luis and Eleonor live in a bubble of their imagination, having a higher level of wishful thinking correlated with a higher level of anger. Usually, distraction predicts poorer outcomes, such as anxiety, disruptive behaviors, and poorer physical health (Littleton et.al. 2007; Moscowitz et.al. 2009). Although, when the

stressor of perception is uncontrollable the outcomes are more negative relieving stress (Clarke, 2006). Thus, under these circumstances, controlled expressions are more beneficial against the stressful events (Austenfeld & Stanton, 2004). Respectfully, Luis believes that very soon he will be an outstanding football player and earn a lot of money in a short time to help his family, and Eleonor at 12 years old still has an imaginary friend to substitute her lack of social connection. Emotional-focused coping relieves anxiety, otherwise considered as internalizing or disengagement, which, can bring about a short-term relief but reduces motivation to return to a stressor, thus, minimizing engagement (Lengua et.al., 1999).

Ricardo encouraged by his family members approaches more problem-solving strategies. The domains of problem-solving are an outcome of planning and disciplined properties of the behavior that makes the engagement more likely (Vollrath, 2001). The example of the family persistence and motivation has given him a set of purposeful action to increase coping strategies. Actions under a conscious condition and strong will, predicts cognitive restructuring and capacity to disengage from powerful negative thoughts (Derryberry et.al. 2003). The sense of optimism in achieving success is positively related to problem-solving such as social support. As a result, optimism predicts active attempts to both change and accommodate less stressful circumstances (Solberg-Nes & Sergestrom, 2005).

Alex also has ‘wishful thinking' and sometimes ‘cognitive restriction,' which results in giving him a higher level of anxiety, hoping to make his dream come true and on the other hand repressing it. The tendency to perform avoidance coping amplifies the relationship between high behavior performances including anger (Hasking, 2007). Personality traits are a very important domain of coping strategies. Also the context influences the manifestation of emotional outcomes (Prokopcakova, 2004). Coping strategies can be a voluntary response to stressful events (Compas et.al. 2001) as well as an automatic and involuntary response (Eisenberg et.al., 1997; Skinner & Zimmer-Gembeck, 2007). Problem-solving strategies are usually more related to a planning outcome, while, avoidance is less harmful to a chronic stressor as they are less controllable and amenable to problem-solving (Penley et.al. 2002).

Vanessa is now confident in her future, and searches for problem-solving ways to reduce the level of anxiety (Varni et.al., 1996). Optimism increases the possibility to embrace problem-solving coping strategies. Sometimes, positive coping strategies accommodate stressful circumstances, due to their expectancies for change (Solberg-Nes & Sergerstrom (2005).

Contrary to the experimental group; in the comparative group, Bernardo has a higher distraction and social withdrawal followed by a higher level of anxiety. The social withdrawal increases aggressive behaviors (Bowker, Bukowski, Hymel, Sippola, 2000). Usually, higher levels of anxiety report the more stressful situation and appraise these stressors as more distress provoking (Allen, Rapee, & Sandberg, 2008). Mariana, on the other hand, has higher internalizing points and distraction resulting in higher levels of sadness for her. The more she escapes from social connection, the more her level of anxiety increases (Varni, et.al, 1996). Pedro and Carla have a higher level of sadness although, for Pedro ‘distraction' has more points while Carla doesn't use ‘distraction' per se but has more ‘resignation,' and ‘cognitive restriction.' Cristiano and Liliana use more ‘social withdrawal’ and ‘distraction’ resulting in higher levels of anger and anxiety.

4.5. Assessing art intervention effectiveness modifying/changing coping strategies in children coping with a chronic disease.

Chronic diseases contain 77% of the world’s disease burden, where 10-20% are children, and the most common of which is asthma (Hobbs, 1985). When working with art therapy intuitively, we believe the outcome is successful. This perception rules out other possibilities when art therapy fits as the best solution for a client or worked in the same way for another client. Thus, it is essential to provide evidence of the efficacy of this intervention. There are many people invested in the outcome of the treatment given to clients; most importantly, the clients themselves need to know that the art intervention they are being offered has been shown to mitigate the challenges they face.

Given the complicated clinical dilemmas of the 21st century, at times it can feel discouraging to work in the art therapy field without a reminder that what we are doing not only has meaning but also makes substantial headway in the areas where our clients are facing problems. In the midst of completing this review of outcomes research, the study was encouraged by the involvement of the clinical cases in the art intervention sessions.

Art therapy uses creative expressions to provide individuals with a safe outlet for expressing thought and emotions to facilitate recovery from distress successfully. Some therapists consider drawing as a privileged access to the child's unconscious (Ciccone & Lhopital, 1991). It leaves a place where children express themselves, and at a later time, the therapist can try to decipher and use it, in the way the children give the key to his unconscious message. In the drawing, the child can build an imaginary scenario in which he is always present with his/her real needs, perceptions or fear, desires, aspirations, memories, and experiences. The child projects into the design as: "the child casts over as wonderful thinks that he/she carries within." In this sense, the children project their self-image in space. Therefore, the design becomes a story that children tell. It is an important therapeutic alliance that allows the child liberation from anger, discontent, fear, etc.

On the psychological point of view, the condition of a suffering body and the risk of sudden pain represent catastrophic experience, especially because if it happens during the evolutionary phase, the child lives in his/her own powerless bubble (Ciccone & Lhopital, 1991). These experiences can then be amplified by the feeling of the child to be impotent in facing the disease, because of the pain, anxiety, physical symptoms, and unwanted side effects of treatments. The opportunity of expressing the anguish, however, can be very different from patient to patient (Odero et.al. 2005). According to Gelli et.al. (2004), children can maintain a sort of double track in understanding their disease. On one hand, they have to organize their coping mechanisms away from conscious awareness, so moving fear and pain. On the other hand, they need not be alone when faced with anxiety and emotions that parents and health care providers can understand without being overwhelmed by fear and help them to cope.

Art therapy can be seen as a powerful tool for encouraging children dealing with a chronic disease, observing their board games, designs as a crucial key to an invitation for an open conversation. Eleonor, for instance, was the most difficult case among the participants in the experimental group. Initially, she refused the invitation to participate in the sessions, always requiring the presence of her parents. The colors and the tasks in the sessions freed her need for protection and woke her up from the imaginary work she has designed. Eleonor committed to collaborating, and the outcomes were very impressive. For the first time in a hospital environment, she accepted to stay without the presence of her parents, relying on her ability to create a relationship with the health care professionals. The coping mechanism can be voluntary and involuntary. Therefore, to study and modify them first it's important to examine the situational context and central personality traits (Lazarus, 2006). Art intervention compiled its scope to arrange all the puzzles in order to have the big picture.

Through art therapy, children can also learn how to manage difficult emotions such as fear and anger, and they also learn coping responses through visual images, especially when they have difficulties verbalizing situations (Eaton et.al. 2007). In such troublesome situation a child uses verbal communication cautiously. At times, he/she feels fear and embarrassment around strangers and parents as well, especially when they are speaking with the health care professionals. Moreover, inside a hospital, a child feels like a stranger because of the uneasiness that accompanies the hospital experience. Good communication is essential in order to establish between patients and caregivers that lead to mutual fulfillment (Subbotsky et.al. 2010; Ewing, 2008). Alex and Luis lived in repressed anger as well as fear for the uncertain future. Solution-focused approach combined with art intervention offered a new perspective to see the problem. They had to perceive the situation through a different spectrum, generating solutions here and now for the immediate problem, and leave aside the anger. The use of the common language of art may facilitate the development of a relationship with the health care professionals, and the parents. This result, sometimes, can be achieved with the help of nonverbal tools such as music and dancing for Alex, and football for Luis, in order to establish a positive alliance.

The language of children and adolescents is unsophisticated. They express themselves through drawings, using a stage to dramatize their request, need, wishes, anxiety, and joy. They use symbols and images to represent elements in circumstances they are trying to understand. The opportunity to express themselves through verbal exchange and drawings offers a safe environment to self-heal mechanisms (Huss et.al. 2012). Vanessa, despite being 16 years old, didn't know how to use the power of communication with her parents. The consensus among the coping studies is that problem-focused, cognitive, or approach strategies generally are related to better adjustment (Brown et.al., 1986; Fields & Prinz, 1997). Solution-focused approach, in this case, came to help more than the art intervention, to divide the problem into small sections and deal with them separately. If you see the problem at once, it's scary to face it and deal it, but once chopped into smaller parts, then the solution is not hidden anymore (de Shazer, 1991).

Perception of the disease, as well as fears and hopes, emerge. The comments from children and adolescents, allow one to acquire a better understanding of the person who draws meaning and feeling (Alavinezhada et.al. 2014). Ricardo for instance, runs a marathon of unstable health conditions during the sessions. He learned how to pick the right message from the troublesome events and use it to the best of options. Solution-focused approach is a key element to art intervention, offering children solutions created by themselves and a breath of the victory of discovering your resolution (Molinar & de Shazer, 1987).

Drawing performs two functions: a function of releasing, in which the child actively reproduces an unpleasant experience, and anguish can be externalized. The second function is symbolic in which the children immerse themselves in a fantasy world where every desire can be accommodated and realized, creating a symbolic play, through which the child can express emotions (Caprino, Naselli, Massimo, 2016).

4.6. Person Picking an Apple from a Tree impact on Problem Solving variable

A drawing of a Person Picking an Apple from a Tree (PPAT) is a projective technique, a method for obtaining psychological measurements through self-report with a minimum of the participant's conscious cooperation. According to Gantt and Tabone's (1984) instructions, for all drawings, children were offered white drawings papers (A4 format) and 12 colors (red, orange, blue, turquoise, green, dark green, pink, purple, brown, yellow, black, and magenta). Drawings were scored using the Formal Elements of Art Therapy Scale (Gantt & Tabone, 1998), extracting the 8th variable, problem-solving, as the key assessment to art intervention to identify coping strategies.

Problem Solving can be related to affect and can reflect feelings of helplessness and coping ability. As mentioned earlier, it was beyond the scope of this study to dwell on symbolism in children's drawings. FEATS Problem-Solving Scale measures the degree to which the individual shows the drawn person picking the apple from the tree. Drawing a person picking an apple combines two distinct abilities: the ability to understand the challenge bound to the concept of a person picking fruit from a tree, that is, a higher object; and children's ability to draw a person in action. The verbal exchange with the children during the last sessions turned the session into a very constructing task for the Problem-Solving technique. Five out of six participants picked the apple thinking of a specific goal and came up with strategies to achieve it. Their coping strategies were measured through the questionnaires, highlighting the changes in coping mechanisms.

As mentioned in the theoretical background, it was beyond the scope of this study to dwell on symbolism in the children's drawings, especially when using drawing techniques designed to simply score only one rating scale, Problem Solving. Although a descriptive table computing the symbolic content of the drawings is shown in the table 20.

Lowenfield theory (1947) held the conviction that artwork produced by children manifested all aspects of their growth including psychological, social, cognitive, and physical development. Thus, coping strategies need to be tailored to the children's individual development and cognitive ability (Piaget & Inhelder, 1969).

The data gathered suggested that all the participants had an appropriate color use, logical and balanced composition, several added details beyond the basic drawing problem, realistic depiction of a person and a depiction of a practical strategy for getting an apple out of the tree. In the figure 38 for example, Alex PPAT, shows the tree surrounded by many trees around the apple tree and the placement of the person. This characteristic indicated an understanding of depth perception. The person doesn't have a proportionate size with the tree and the other details around the picture, indicating the participant attention to the greater environment surrounding, and himself very small, showing only the back.

However, the study found that the formal elements of the sample drawings indicated, on average, a lower than their age drawing level. In the case of Ricardo, his drawing had distorted shapes, and different line qualities, due to his physical problems, trembling hands, and eye-hand coordination that hardened the conditions while drawing. The Figure 35 the person is drawn with very few details, and the person's size is not realistic in relation to the tree. The person stands at the same height as the tree.

The participation of the children in the art therapy sessions was on open invitation to provide an empathetic 'seeing' (Rogers, 1969). Despite the family ties and good connections, children need a deeper level of understanding. At first, language barriers may harden the connection, reason why artwork invokes many other occasions to bring specific topic the children were not aware of previously. Such was the case of Patricia and Ricardo getting all the attention from their parents but never feeling really close to them enough to confess their deepest fears. Accepting the person unconditionally during the session relieves the tension (Rogers, 1969) and provides a safer environment for the child to contribute to the art making process.

Young children may in many occasions be unable to understand and remember explanations, thus, they need alternative ways of communication (Eiser, 1986). Solution-Focused approach is a very affective technique to provide effective communication (de Shazer, 1991). It transforms problem-oriented language into solution-focused language (Cooley, 2009). In the case of Vanessa, she was

dreaming big, and fighting for immediate freedom from her parents. Her disease was not impeding her from having a future. She was using it as a mean to achieve her freedom. Climbing the tree was a very interesting approach. She came into the art room ready to complain, as all this time she has repressed this thought within her. She felt accepted unconditionally, despite her background and religion (Rogers, 1969). Vanessa was at a specific point of her life, and that was to find a meaning for her future (Frankl, 1963), that would be less threatening.

Alex and Luis were two exceptional cases. They both came from difficult family situations and they both wanted to grow up as soon as possible to help their families. Alex discovered a talent in drawing and surprisingly also in dancing. These two talents helped him to become noticed for something, especially by his mother. Whereas, Luis, had to start making baby steps till he achieved his goal. That would require him to accept his health condition. Alex drawing of PPAT was somehow a success. He described it as a surprise and effective because he was finally being noticed and starting to have friends.

Regarding Ricardo, he was one of the most complicated cases, especially from his health condition point of view. Ricardo had a very positive spirit helping him overcome many difficult moments. His love for football though was a meaning for his fight (Frankl, 1963). Despite his difficulties with drawing, he kept on working and got seriously involved with the tasks. He is reaching out for the apple, although the hand is lost among the leaves, he knows he can't have easy things because of his health problems, but he still searches for other less threatening options (de Shazer, 1991).

PPAT is a sensitive art based tool for the expression of the children's problems, especially if we make a gender difference between girls and boys. When children struggle with poor meta-cognitive functioning, their PPATs tend to reflect a passive person, with a tree trunk that inclines away from the person and low degree of picking success (Bat et.al., 2014). Such is the case of Vanessa, climbing the tree while the trunk of the tree is missing but the branches incline on the other side she illustrate the person climbing. However, many apples are drawn next to the person. Through the bending tree, the child

clearly represents a negative aspect in the relationship between the two objects (tree and apple) (Bat et.al., 2014).

Based on gender differences that were found in Young (2005) study speculated that girls suffer more stigma, loss or social status, and emotional problems than boys, presumably because they differ more markedly from gender-based expectations of performance. This explains the presence of negative aspects in girls' PPAT in comparison to boys, when the avoiding tree might represent the girl's subjective experience in object-relations. Interestingly, the three girls participating in the study expressed a strong need for social connection. Patricia is blaming her disease and body problems for the lack of friends at school, while Eleonor lives in an imaginary world, inventing an imaginary friend to fulfill the need for friends. Vanessa as an adolescent craves for freedom, reason why the trunk of the tree is missing.

Alex and Luis showed a higher level of anxiety from the test, also the seven session of art intervention. Boys with high level of anxiety tend to draw the task as difficult, illustrating the branches far from the person. This may represent their perception of requested goals as unreachable and a script that might heighten their anxiety a priory (Bat et.al., 2014). Alex illustrates a very small body far from the tree, reaching an apple that stands far from his hands. Luis as well, stands far from the tree, even though standing on a chair to reach the apple, he the branches are far from his hands. Unconsciously, he is accepting that his dream to play football as a professional and be rich can be very far and difficult to reach.

An object-relation interpretation would be that the child might represent a stressful alliance in a close relationship, in which, despite of the presence of each object, the drawn person must work hard to get the far apples based on the clinical findings of Greenspan (1992) determining a poor parent-child relationship result in an array of behavioral concern, including anxiety. Cases like Alex and Ricardo showing some social problems, they tend to depict a more active person in their PPAT. A dynamic explanation could be that the activity of the person symbolizes the child's active efforts for social acceptance in the face of rejection and/or loneliness (Bat et.al., 2014). This explanation is based

heavily on psychoanalytic ideas in which the act of drawing is a projective method for the child's inner wishes in the face od his subjective reality (Tronick et.al., 1978). In infant studies, where infants when infants were confronted with a still face (which resembles a social rejection) they work hard to regulate their affects by self-soothing and distraction strategies on one hand, and by actively trying to change the context, for example, protesting (Adamson & Frick, 2003). Luis and Alex chose the second strategies, protesting for attention and ask to be visible in the eyes of their parents.

At first, drawing a person seems active in investing extensive efforts in attaining a hard-to-reach goal. Then, these drawing of an active person might also reflect a possible coping strategy by focusing attention on reaching constructed goals as a distraction from the frustrated social realm. By distracting themselves, children temporarily shift their attention to a more pleasurable activity (Drake & Winner, 2013).

4.7. Educators reflection on the art intervention

Two main educators followed the sessions procedure from closer, as they participated in various meetings during the research procedure. The other six educators witnessed the process through conversations with parents and the children themselves involved in the research. Their involvement in the study was very coordinative functional oriented. At the end of the study procedure, all the educators and two nurses involved in the study, participated in a meeting debriefing their impressions and reflections on the art intervention at the hospital.

> *"I am a new educator from the Consulta de Desenvolvimento. I came in September in the Pediatric Unit, and I was expecting months and months till I would know all the children. When… I got so surprised in just 20 days, I already knew five of them, that come very often at the hospital, asking me questions, and wanted to draw. For me, it was the easiest way to talk to children."*

Four out of six educators shared the concern that their profession was not very well respected in the pediatric union, as they don't have a medical degree. They defined this indifference among professionals as a lack of communication. The reason why, five out of six educators, felt very good involved in the program. Their involvements increased the connection with other professionals, arranging the children's schedule, and discussing the treatment plan.

> *"Well, I am going to say this…. Before the pediatricians wouldn't talk to us so freely. We had to call them Doctor X or Doctor Y… but this time we didn't pay so much attention to the titles."*

Regarding the nurses, they considered these months as an experiment for themselves to participate actively in the medical treatment. One of them shared this moment:

> *"When Alex came to me asking about his pain, I was in shock! I told myself, is this real? I know this boy for so long, and he never talks to me."*

The educators have been closer to the children in the activity room. They found parents connecting with each other, and discussing issues of their children, using art sessions as a conversation opener.

> *"Ricardo's mother is always very shy. The poor woman spends almost 7 hours in the hospital and sometimes the boy has severe symptoms, and she never complains. Lately, she is very interesting in the drawings you are doing, and every day reads something new about it. She then discusses it with us in the hospital."*

Some other educators expressed openly their need for training.

> *"Yes, what you did was beautiful. I mean, seeing that boy talk (Alex), it was a miracle. I am going to ask something… Can we also learn how to do what you did? I am very interested to have some training so that we could also help to have this results."*

Interestingly, one of the educators coming from the Consulta de Desenvolvimento has been very affectionate to one of the participants in the experimental group. She shares:

"Eleonor, I love her family. Beautiful parents, but the girl is so indifferent. In the beginning, they thought she was autistic, but then she started to talk. She never looks in the eye. One day I saw you holding her hand and talking to her, I thought that this was a miracle. That girl has never talked to anybody in the hospital, and we try everything to involve her in games."

The other educator expressed the concern about one girl she has been following for a long time. Vanessa, participated in the art sessions, and her impressions were:

"I thought that girl would run away from home. Sometimes, I thought why do they bring her so often at the hospital; she doesn't have the need for this strict treatment. At the beginning she rebelled, chewing when talking, saying bad words. I don't know how much this thing will continue, but one day during her medical treatment, she was looking at my hand and started to plan how to make my manicure, asking me to be her client. I got surprised, so I accepted. She came the next month, and she was so nice, smiling and talking about her new plans……. Now I don't know what did you do in the sessions, but I am very happy."

Their suggestions were many and through the discussions they provided with very interesting feedback.

"I would have liked this project to continue longer. I just entered in the Pediatric Unit, and want to see more."

……

"For me, I am surprised. If I could suggest something it would be to make groups of children and not only individual meetings. I think this could help also."

……

"In our unit we have many little children. Can you use art with this category of children? I think it can be very helpful for the parents!"

…...

"I would suggest to involve more us, the educators in the sessions. I don't know if it's allowed but, I would have liked to hear more how did the session go."

…..

"I liked you… we had other students doing a research and they usually got involved with us more, or the parents, and usually they would mix the information. I think, it was your strategy, I am not from your field, but I think it was very good of you not mixing the connection with other professionals. You just focused with the children, and that helped them to trust you!"

At the end of the meeting, unanimously, all the educators and the nurses asked for training regarding the art intervention at the hospital.

4.8. Study limitations

Successful studies can provide information about the specific case studies and about similar groups or individuals. However, given a small sample size in the quantitative dimension, the results of this study may have some lack of precision and may not be generalized to other similar populations. The number of participants in this research study was very limited especially due to the inclusion criterion. It was very difficult for the educators at the Hospital Santa Maria, to select children 7-18 years old diagnosed with a chronic disease without any cognitive and physical impairment. Most of the patients at the hospital had severe symptoms, underage, and unable to continue regularly 7 sessions, as their hospital visits would be unpredictable.

Regarding the qualitative dimension, this study has more the characteristic of a case study providing in depth understanding of the coping strategies children settled in a hospital environment. Studies describe the inter and intra-individual aspects of coping in regard to situational determinants, differing from one another in accordance to the context (Frydenberg, 2004).

In continuity, the limited number of participants constricts the chances to perform formal statistical hypothesis tests. Such, the project is an exploratory intervention study functioning as a source for developing ideas and suggestions for further research investigations. During the 12 months of study intervention the six children participating in the experimental group showed interest and involved actively in the a art intervention sessions. At first the language barriers could have jeopardized the communication, but it turned out to be a facilitator for the bonding between the researcher and the child, reason why the sessions didn't only include performing of the tasks but also spontaneous activities with the child such as dancing, playing football, storytelling, etc.

Every art intervention session was scheduled in advance with the collaboration of the educators and the hospital nurses. Due to their health conditions and unpredictable emergencies, we had to reschedule sessions adapting the intervention plan to their needs. The collaboration with the nurses at the hospital, became a significant advantage to the study, notifying in advance any change made from the previous schedule.

At last, during September, the children were already in their fifth art intervention session, the educators had to rotate shifts with their colleagues from the Centro de Desenvolvimento. Every educator had the program of the study from the beginning of the project, but the new educators didn't know the participants in the experimental group. Thus, at first, it was a hesitation for children to bond with them. Interestingly, very important moment happened after the sixth session. Children became soon very close to the new educators and participated in many activities they were organizing (refer to the Educators reflection on art intervention).

CHAPTER 5

CONCLUSION AND RECOMMENDATION

5. CONCLUSIONS AND RECOMMENDATIONS

Children coping with chronic disease undergo a marathon of long hospital visits and medical treatments for a long period of time. The hospital setting itself can be a source of both hope and distress to the ill child and his/her family (Malchiodi, 2007). Through naming a condition and beginning treatment, there is hope for cure and relief from suffering, the medical environment itself can feel like a foreign land. A visit from the art therapist, a grown-up who brings art materials, and an invitation to draw or paint, as opposed to needles or pills to swallow, can be instantly comforting to a frightened child. Also, the communication between the health care professional and the child/teenager is very important in three main areas: understand, prepare and better cope with the chronic condition; help to have a smooth discharge from the hospital; and prevent any relapses after the discharge.

To the eyes of a patient, a nurse or pediatrician is someone that offers authority and represents medical treatment. In the best of cases, the art therapist mediate this interaction between the two parties, helping the child adapt better not only to the hospital condition, as well as empower them to take care of themselves, and increase the self-awareness about their symptoms. The art sessions at the Hospital Santa Maria, offers a friendly environment to the children and adolescents that need frequent medical treatment. The session room is also one of the most important spaces in the hospital.

Coming into the room alone (without the presence of the parents) gave the children a certain amount of confidence, as the space was where they showed their personal interest and talents, gained friends, cried, and laughed, danced, sang, etc. That room became their safe space, that didn't represent anything from the hospital, but served as a bridge to the medical treatment after each session. The art intervention didn't focus on their ability to draw as opposed to what they were drawing, what colors they needed to use. Conclusively, the psychological service can help develop a scale to evaluate the cognitive and physical development, but the art/psychological sessions empowered the

children to understand the chronic condition of their disease, prepare them for social life, and mediate communication with their parents and pediatricians.
As opposed to the other therapies, especially the cognitive/behavioral, this is considered adaptive for hospital conditions because of behavioral problems that children develop when they go to the hospital. The Solution-Focused therapy (de Shazer, 1991) offers a goal-oriented therapy, find solution and its main focus is to strengthen what works as opposed to finding problems (Molinar & de Shazer, 1987). From the administration of the Solution-Focused therapy, these techniques combined with the art intervention offer a perfect approach for a short-term intervention and strengthening of the positive coping strategies they were already in use. Interestingly, strengthening the connection with the parents, or using the hidden talent, or freeing the dream to become reality, serves as a crucial key to their improvement and shaping the coping mechanisms as well.

Combined with Drawing a Person Picking an Apple from a Tree (PPAT) (Gantt, 1990), it is useful in evaluating coping ability and resourcefulness. The drawing encourages the child to depict the situation and solve the problem. The PPAT test is a very well-known intervention in many researches with children coping with chronic conditions, but none of them is combined with art sessions based on the solution-focused therapy.

This is the first attempt to combine the art therapy with the PPAT test, preparing the child to imagine the problem and the difficult situation, and at the end leaving him/her alone to find the independence and develop solutions. The test implemented at the end aims to give a continuity of their process of thinking, and encourages them to trust their solutions by remembering the results achieved up to the end. Providing a continual support at the hospital for every child reduces the frequency of emergencies. As described from the art sessions and educators feedback, children started to be more involved in regard to their health conditions, asking questions, and collaborating with them at the hospital, improves the collaboration between the health care professionals and the

patients, as well as empowers the child to find confidence and control his/her health conditions alone.

The first theory on coping was proposed by Lazarus and Folkman (1984) defining coping as “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised of taxing or exceeding the resources of the person” (p.141). However, this definition has some limits because they don’t clarify or provide evidence of other developing subsystems such as cognitions, language, age, etc. As a result, different researchers based on the first definition, extended the concept over the past ten years conceptualizing it as “regulation under stress” (Compas, et.al., 2001; Skinner, 1999; Eisenberg et.al., 1997). Many up to date researchers postulated that coping behaviors are fairly stable, remaining consistent across various situations (Donaldson et.al. 200; Spirito et.al., 1994; Spirito et.al. 2001). This explains that children’s coping behaviors are the same to different types of stressors such as pain, lack of friends, health conditions, family situations, etc. Furthermore, researchers found that the children’s behaviors can be more stable than that of adults (Compas, Malcarne & Fondacaro, 1988). But very few attempts have been made to evaluate coping behaviors and their frequencies utilizing an appropriate intervention. Every research attributes stress to a specific field of life such as cognitions, health, business, etc. Each of them has also developed specific subscales to measure coping. Having many subscales usually confuses researchers (Compas et.al., 2001). As a result they make it difficult sometimes or even impossible to aggregate all the researches into one big conclusion, nor to compare different ways of coping.

Up to date, coping measurement has created confusion to accumulate knowledge from explanatory and intervention efforts (Sandler et.al., 1997). Skinner et.al. (2003) concluded that all these disagreement interferes with methodological progress, developing alternative questionnaires methods presents a greater challenge. PCQ and KidCope are two compatible questionnaires, using different subscales of coping but always dividing among the three scales of coping ‘approach’, ‘distraction’, and ‘emotion-focused

coping'. In both questionnaires, despite their diversity in subscales, measuring strategy, questions typology, and the conclusions reach the same point, as well as including the conclusions achieved from many other previous researches (Varni, et.al., 1996; Goodman & McGrath, 1991; Van den Bree et.al., 1990, Compas et.al., 2001, Skinner, 2003). Thus, both questionnaires, despite their distinctive scales and subscales, provided same findings to measure the effectiveness of the art intervention sessions.

Crucial observation, there is lack of research using intervention as a means to emerge coping strategies, observe their rigidity and flexibility, as well as time necessary to provide a modification of coping. It has been argued many times that because of the complex, changing nature of coping, traditional psychometric evaluation measures may not be appropriate. Stone and Neale (1984) pointed out that within particular coping dimensions; the use of one or two specific strategies in fact decreases the need to use strategies in that scale. This fact would place a ceiling on internal consistency coefficients. Also, if coping is a dynamic process, changing over time, it may not be surprising that when the same coping measure is used with different samples and different settings, the factor structure varies (Aldwin & Revenson, 1987). To the best of my knowledge this study serves as the first research that uses art/psychological intervention to study the response of coping strategies, (if coping changes over time) as well as their scale and subscale remodeling in a short period of time, using two different coping measures.

Furthermore, Varni (1995) offered a new theory of coping entitled 'Biobehavioral Model of Pediatric Pain'. As a response to this concept, they described a number of factors that influence pediatric pain perception and have associated functional status outcome parameters. On the first group there are the individual factors disease (e.g. the chronic condition, epilepsy, rheumatism, cancer, diabetes, etc.); physical injuries (e.g. medical procedure of treatment); biological predispositions (e.g. genetic, age, personality traits, etc.); then there are the intervening factors such as family environment (e.g., economic situation, family harmony, number of members, etc.); cognitive appraisal (meaning of pain);

coping strategies (e.g., distraction, social withdrawal, problem solving, etc.); and perceived social support. Then, there are functional status variables (e.g. daily activity, school attendance, anxiety, and behavioral problems); as well as the pain antecedents (e.g., duration of pain, intensity of pain, etc.). This integrative multifactorial model includes many variables to measure the chronic condition for children and adolescents, reasons why researches slow the path of discovery dividing or including only a few variables at the same time, making it impossible to overpass this obstacle.

On the other side, interventions, such as psychological intervention require more time and less number of participants, but they are one of the few possibilities to offer a broader prospective of the model, including most of the factors and reaching a convergence at the end with one another. Coping mechanism can be voluntary or involuntary, but the only way to study them is to take into consideration the context and the personality traits (Lazarus, 2006). Children with chronic diseases are a neglected group of study, because the main part of the research bases their conclusions on results from adult participants, as this category shows evidence of the level of economic burden (Goodman & McGrath, 1991). Children on the other side offer economic burden in different aspects such as school absenteeism, continued medication, continuous visits at the hospital, etc. Thus, researches using children/adolescents as the main participants are very few. This study uses children as the main participants to analyze coping strategies. More researches involving children actively in the research are needed for future references.

From many past studies (Kashani et.al., 1992; Lavigne & Faier-Routman 1999) have been settled that the results from the children themselves are contradictory with those of the parents regarding the pain perception. Such was the condition with this study, where parents from both groups, after showing the results from the first administration of the APPT, were confused, and had difficulties believing the child was referring to pain (chronic or reluctant pain) as ‘horrible, unhappy, makes me cry, makes me scream, soar, etc.’ Children and adolescents show a higher rate of freedom when the parents are not present

while filling the questionnaires. The results from the questionnaires for the reference comparative group for instance shows almost the same results after six months, taking into account that they didn't undergo any intervention or take part in any training about their health conditions.

At last, the combination of PCQ and KidCope questionnaires adapted to every specific situation developed by Varni and his colleagues (1996) statistically proved the effectiveness of the art intervention. Despite their different utilization and coping domains, the findings for each of the children were similar in both assessments. However, coping has never been measured as a changeable variable in any previous research. Through continuous intervention, the coping subscale can be modified within a short time, as a process of elaboration of coping concept and psycho-education about health conditions. The study showed that the art intervention can modify, and change coping behaviors in a short time. As confirmed by the hospital staff, hospital environments are in dire need of a multidisciplinary team to broaden the collaboration among professionals and offer holistic services to the patients. The visits at the hospital can be more entertaining and relaxing if the environment is prepared to fit to every need of the child as well as the parents. Future researches are needed to evaluate if the new coping behaviors are persistent in time.

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APPENDICES

Appendix A

Letter of Consent

Letter of Consent

Escola Nacional de Saúde Pública
Hospital de Santa Maria

Date: ____/____/_____

Dear _____

You are being invited to participate in a doctoral research study on Public Health with children coping with a chronic disease. In particular the research is interested to regenerate new positive coping strategies while dealing with the pain and daily symptoms of the chronic condition. The researcher is interested in studying the role of art therapy, which involves drawings (directed and free expression of images) during the time the children are at the hospital having their regular intervention.

This research will take maximum 10 sessions (1 introduction session, 2 sessions of surveys, and 7 art intervention sessions). During this time the children will participate for one hour every session in an exclusive environment at the hospital Santa Maria, Lisbon, Portugal. Before starting each session, the parents will have detailed information on the procedure and the materials to be used while working with the child. The session consist of the presence of the child and the researcher, in an exclusive room compound by a table, chairs, and the materials for drawings such as paper, colors, specific toys in accordance to the child's need. At the end of the sessions the parents will have a brief description of the activity performed in the room. At the session number one and the last session the children will fill three questionnaires related to their emotional and physical conditions. The parents will previously read the questionnaires.

There are no anticipated risks or discomfort related to this research. However, if you feel uncomfortable with any part of this study at any time, you have the right to terminate participation without consequences.

You may find the participation in this study enjoyable, as it is a chance to have your child perform amusing activities while continuing the hospital procedures. The information gained from the sessions can be very useful in identifying suppressed emotional or difficulties monitoring and coping with the disease.

Several steps will be taken to protect your anonymity and identity. Firstly, the information you will share with the researcher will be confidential. Second, your and your child's name and personal information with be kept confidential as well. Names will be translated into ID codes and all data collected, will be labeled with the ID codes rather than your names. This information till the end of the study will be in the researcher's locked office at the Escola Nacional de Saúde Pública. The only person, other that the researcher and yourself, who will view the raw data will be the researcher's PhD supervisor.

Your participation in this research is completely voluntary. If you choose to participate and then change your mind, you may withdraw from the study at any time for any reason. If you do this, you will have the choice of having the information contributed removed from the study and destroyed, or allowing the information contributed until the time of withdrawal to be included in the study, and that no more information or data will be collected from you from that point on. Again, there will be no consequences to any decision you make.

The results from the study will be reported in general terms in the form of speech, writing, drawings, and presented in manuscript submitted for publication in scientific journals, or oral (poster) presentations at scientific meetings, seminars, or conferences. Your personal information, including your and your child's name, will be kept confidential and not be distributed in any way. If you wish to have a copy of the results of the study, you may contact the researcher through the email gentakulari@gmail.com.

Parent Signature

_____

Appendix B

Informed Consent to Use Artwork

Informed Consent to Use Artwork

I hereby give permission to _____to use my child's artwork in an art therapy research project. I understand that my child's name will not be attached to the drawings and that his/her identity will not be revealed to any of the other researchers involved in the project.

I understand that some of the drawings may be used in professional art therapy publications and presentations but no information, which would indicate the person identity, would be used in conjunction with them.

I understand that my child's art will be photographed and that I have the option to have it stored at the site of the research study and can take my child's art with me at any time during the duration of the art therapy session.

Name:_____ Date: _____

Research Investigator

Name: _____ Date: _____

Research Participant

Appendix C

Consent Information Letter

Consent Information Letter

Tittle of Research Project: Art therapy techniques to improve coping strategies in children 7-18 years old with a chronic disease.

Student Investigator: Genta Kulari

Contact Information for Student Investigator: gentakulari@gmail.com

Principal Hospital Supervisor: Maria Rosario de Botelho

Contact Information for Principal Hospital Supervisor: Mariar.n.botelho@gmail.com.

I have been asked to participate in a research study that is investigating the use of art therapy techniques to improve communication skills and coping strategies with children suffering from a chronic disease. The results of this study should further our understanding of using art therapy techniques as an alternative way to improve coping mechanism for children diagnosed with a chronic condition.

I understand that:

1. My child will be asked to take a survey before the art intervention sessions and after, that should take approximately 1 hour to complete in each time.
2. The possible psychological risks to participate in this study are considered minimal and do not include any discomfort based on reaction to art directives.
3. There may be minor benefits to my child personally in the area of communication, and the results of this study will help expand our knowledge of coping mechanisms in children with chronic health conditions through the use of art intervention.

4. Although alternatives procedures may be used, the present procedure is the most advantageous and economical
5. The results of this study may be published, but any information from this study that can be identified with me will remain confidential and the data will be pooled to maintain anonymity.
6. Any question about my child's participation in this study and project procedure will be answered by Genta Kulari personally or through email gentakulari@gmail.com, or should be addressed personally to the Principal Hospital Supervisor Maria Rosario de Botelho or through email Mariar.n.botelho@gmail.com.
7. My consent will be given voluntarily without being coerced. I may refuse to participate in this study or in any part of this study, and I may withdraw at any time, without prejudice or with any further contact with the Hospital Santa Maria directory.
8. I have received a copy of this document, which allows me to read carefully and understand the conditions and requirements to participate in this project.

A. Purpose and Background

This study aims to gain an in-depth understanding of art therapy effectiveness in improving coping mechanisms for children suffering a chronic disease. An additional goal for participants is to gain the experience of art therapy and the art making process, which will occur during the seven art intervention sessions. The study ultimately seeks how art therapy may be used as an alternative modality to improve children's communication skills, increase their perception and descriptive vocabulary of pain, and create a satisfying relationship with the hospital staff. The research will be conducted by Genta Kulari, attending her Doctoral studies program at the Escola Nacional de Saúde Pública, Lisbon, Portugal.

B. Procedures

In voluntarily consenting to participate in this research study, I understand the following:

1. My child will be asked to take a survey before the art intervention sessions and after that should take approximately 1 hour to complete each time.
2. The possible psychological risk in participating in this study are considered minimal and do not include any discomfort based on reaction to the art directives.
3. Artwork may be reproduced for use in a research thesis and for possible presentation and/or publication. Artwork will be filed and documented after being digitally photographed by the researcher, if desired.
4. The photographic images of the artwork will remain the property of the researcher.
5. The results of this study may be published, but any information from this study that can be identified with me, will remain confidential and the data will be pooled to maintain anonymity.
6. Any questions related to the participation in this study and project procedure will be answered personally by Genta Kulari through email gentakulari@gmail.com or should be addressed to the Principal Hospital Supervisor at the Hospital Santa Maria Rosario de Botelho through her email address Mariar.n.botelho@gmail.com.

C. Risks

There is no foreseeable risk involved in participating in this study. Participants of the research will be advised of possible discomfort such as it may experience any symptom during the art intervention sessions. Educators and pediatricians have agreed to participate in the project and they will check the conditions of the child before entering the session. Participants who are uncomfortable or unfamiliar with the art materials may experience ambivalence or discomfort with the art process. The researcher will discuss these discomforts with each child before the session to modify art interventions or strategies, if they are needed,

to minimize possible risks. The risk to participate may include uncomfortable feelings of emotions and/or amplifications of stress with their perception of the chronic condition. The uncomfortable feelings of emotions may occur as a result of exploring aspect of their health conditions, relationship with other people or family members, relationship with the hospital staff, and procedures that participants are not aware of or are neglecting. The researcher will be available during the study to help participants process any discomfort that may arise.

D. Benefits

The benefits of participating in the art therapy sessions for children coping with a chronic disease consists of participants potentially gaining self-awareness of their coping mechanisms, understanding and evaluating pain, clarifying their conflicts, and accepting their health condition. There also may be other possible benefits associated with the participation in this research study. The participants may experience additional support and understanding of their social/health situation. They may find an increase in their ability to communicate with a family member or hospital staff. Participants may gain self-awareness that could increase their confidence. Being in a natural and supportive session environment has the potential to be validating and empowering for children that may have difficulties in their family/social relationships.

E. Confidentiality

The diary, notes, and any possible record from this study will be kept confidential. No individuals will be identified in any reports or publications resulting from the study. All artwork, tests, questionnaires, and transcribed materials will be coded with a number that matches the corresponding consent and permission to use artwork forms. All research information will be kept by the researcher for three years (seven years if published) and used only for research purposes. Unless published, all artwork and testing information will be destroyed after the three year period.

F. Alternatives

This research study involves human subjects and participants. I am free to decline to participate in this research study. I will be clearly informed that I can withdraw at any time with no consequence and all data and personal information will be destroyed and kept confident.

G. Costs

There will be no costs to me as a result of participation in this research study

H. Compensation

There will be no monetary compensation for my participation in this research study. The hospital visit will continue be the same, providing breakfast in the morning for the children, before starting the intervention sessions.

I. Questions

Any questions about the participation and art procedure in this study will be answered by Genta Kulari personally or emailing her at gentakulari@gmail.com. Any questions or concern about security or time should be addressed to the Principal Hospital Supervisor Maria Rosario de Botelho Mariar.n.botelho@gmail.com.

I HAVE MADE A DECISION WHETHER OR NOT TO PARTICIPATE

Please check one:

_____ Yes, I agree with the conditions of the research study and accept to sign a formal consent to be part of this project.

_____ No, I do NOT agree with the conditions of the research study and refuse to sign a formal consent to be part of this project.

Appendix D

Pain Coping Questionnaire (PCQ)

Age (*in years*) _____ Sex (*circle*): Male Female Grade _____

COPING WITH PAIN (PCQ)

Everyone has had a time when they have been hurt or in pain for a few hours or longer. For example, you might have had a headache, a stomach ache, a bad muscle pull, pain in your joints (elbow, knee), back pain, an earache, or, for women, menstrual pain, etc. Below are some things that people might say, do, or think when they are hurt or in pain. We are interested in the things you do when you are in pain for a few hours or days.

Circle one number for each question to show how often you do each thing listed:

1=never, 2=hardly ever, 3=sometimes, 4=often, or 5=very often.

WHEN I AM HURT OR IN PAIN FOR A FEW HOURS OR DAYS, I ...	*Never*	*Hardly ever*	*Sometimes*	*Often*	*Very often*
1) Ask questions about the pain.	1	2	3	4	5
2) Focus on the pain and see how I can make it better.	1	2	3	4	5
3) Talk to a friend about how I feel.	1	2	3	4	5
4) Tell myself, don't worry everything will be ok.	1	2	3	4	5
5) Go and play.	1	2	3	4	5
6) Forget the whole thing.	1	2	3	4	5
7) Say mean things to people.	1	2	3	4	5
8) Worry that I will always be in pain.	1	2	3	4	5
9) Ask a nurse or doctor questions.	1	2	3	4	5
WHEN I AM HURT OR IN PAIN FOR A FEW HOURS OR DAYS, I ...					
10) Think about what needs to be done to make the pain better	1	2	3	4	5
11) Talk to someone about how I am feeling.	1	2	3	4	5
12) Say to myself, be strong.	1	2	3	4	5
13) Do something fun.	1	2	3	4	5
14) Ignore the pain.	1	2	3	4	5
15) Argue or fight.	1	2	3	4	5
16) Keep thinking about how much it hurts.	1	2	3	4	5
17) Find out more information.	1	2	3	4	5
18) Think of different ways to deal with the pain.	1	2	3	4	5

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ID#: SCD_____ Date: _____

WHEN I AM HURT OR IN PAIN FOR A FEW HOURS OR DAYS, I ...	Never	Hardly ever	Sometimes	Often	Very often
19) Tell someone how I feel.	1	2	3	4	5
20) Tell myself, it's not so bad.	1	2	3	4	5
21) Do something I enjoy.	1	2	3	4	5
22) Try to forget it.	1	2	3	4	5
23) Yell to let off steam.	1	2	3	4	5
24) Think that nothing helps.	1	2	3	4	5
25) Learn more about how my body works.	1	2	3	4	5
26) Figure out what I can do about the pain.	1	2	3	4	5
27) Talk to a family member about how I feel.	1	2	3	4	5
28) Say to myself, things will be ok.	1	2	3	4	5
29) Do something active.	1	2	3	4	5
WHEN I AM HURT OR IN PAIN FOR A FEW HOURS OR DAYS, I ...					
30) Put the pain out of my mind.	1	2	3	4	5
31) Get mad and throw or hit something.	1	2	3	4	5
32) Think that the pain will never stop.	1	2	3	4	5
33) Try different ways to make the pain better until I find one that works.	1	2	3	4	5
34) Let my feelings out to a friend.	1	2	3	4	5
35) Tell myself, I can handle anything that happens.	1	2	3	4	5
36) Do something to take my mind off the pain.	1	2	3	4	5
37) Don't think about the pain.	1	2	3	4	5
38) Curse or swear out loud.	1	2	3	4	5
39) Worry too much about the pain.	1	2	3	4	5

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ID#: SCD_____ Date: _____

PCQ 2

Appendix E

KidCope

KidCope: Child/Adolescent Form (Spirito, A.)

First Name:_____ Date:_____

Age:_____ Grade:_____ Boy_____ Girl_____

Instructions: We are trying to find out how children and teenagers deal with different problems after they have been diagnosed with a chronic condition. Below is a situation that may be difficult for you to deal with- Please read the situation and answer the following questions.

SITUATION:

THE EXPERIENCE OF HAVING A CHRONIC CONDITION

Please answer the following questions by circling your response:

1. Does this situation make you nervous?

Not at all A little Somewhat Pretty Much Very Much

2. Did this situation make you sad?

Not at all A little Somewhat Pretty Much Very Much

3- Did this situation make you angry or mad?

Not at all A little Somewhat Pretty Much Very Much

Now please turn over the sheet and circle whether you used any of the following ways to help deal with situation.

	Did you do this?		How much did it help?		
1. I just tried to forget it.	yes	no	Not at all	A little	A lot
2. I did something like watch TV or played a game to forget it.	yes	no	Not at all	A little	A lot
3. I stayed by myself.	yes	no	Not at all	A little	A lot
4. I kept quiet about the problem.	yes	no	Not at all	A little	A lot
5. I tried to see the good side of things.	yes	no	Not at all	A little	A lot
6. I blamed myself for causing the problem.	yes	no	Not at all	A little	A lot
7. I blamed someone else for causing the problem.	yes	no	Not at all	A little	A lot
8. I tried to fix the problem by thinking of answers.	yes	no	Not at all	A little	A lot
9. I tried to fix the problem by doing something or talking to someone.	yes	no	Not at all	A little	A lot
10. I yelled, screamed or got mad.	yes	no	Not at all	A little	A lot
11. I tried to calm myself down.	yes	no	Not at all	A little	A lot
12. I wished the problem had never happened.	yes	no	Not at all	A little	A lot
13. I wished I could make things different.	yes	no	Not at all	A little	A lot
I tried to feel better by spending the time with others like family or friends.	yes	no	Not at all	A little	A lot
15. I didn't do anything because the problem couldn't be fixed.	yes	no	Not at all	A little	A lot

Appendix F

Adolescent Pediatric Pain Tool (PPAT)

Adolescent Pediatric Pain Tool (PPAT)

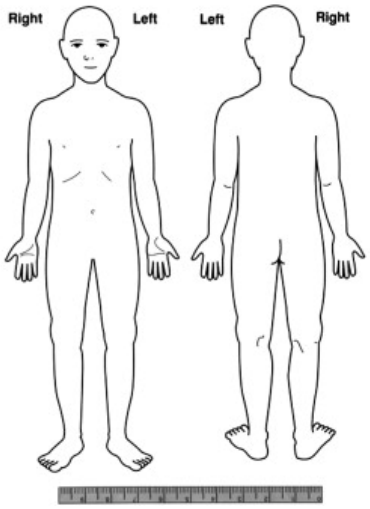
CODE _____

DATE _____

ADOLESCENT PEDIATRIC PAIN TOOL (APPT)

INSTRUCTIONS:

1. Color in the areas on these drawings to show where you have pain. Make the marks as big or small as the place where the pain is.



2. Place a straight, up and down mark on this line to show how much pain you have.

No Pain | Little Pain | Medium Pain | Large Pain | Worst Possible Pain

3. Point to or circle as many of these words that describe your pain.

1
annoying
bad
horrible
miserable
terrible
uncomfortable

2
aching
hurting
like an ache
like a hurt
sore

3
beating
hitting
pounding
punching
throbbing

4
biting
cutting
like a pin
like a sharp knife
pin like
sharp
stabbing

5
blistering
burning
hot

6
cramping
crushing
like a pinch
pinching
pressure

7
itching
like a scratch
like a sting
scratching
stinging

8
shocking
shooting
splitting

9
numb
stiff
swollen
tight

10
awful
deadly
dying
killing

11
crying
frightening
screaming
terrifying

12
dizzy
sickening
suffocating

13
never goes away
uncontrollable

14
always
comes and goes
comes on all of a sudden
constant
continuous
forever

15
off and on
once in a while
sneaks up
sometimes
steady

If you like, you may add other words:

_____

_____

_____

For office use only.

BSA: _____		
IS: _____		
#S (2-9)	_____ /37 =	_____ %
#A (10-12)	_____ /11 =	_____ %
#E (1,13)	_____ /8 =	_____ %
#T (14,15)	_____ /11 =	_____ %
Total	_____ /67 =	_____ %

ADOLESCENT PEDIATRIC PAIN TOOL

APPT – VERSÃO PORTUGUESA (PT)

Versão original: Savedra *et al.*, 1989, 1992

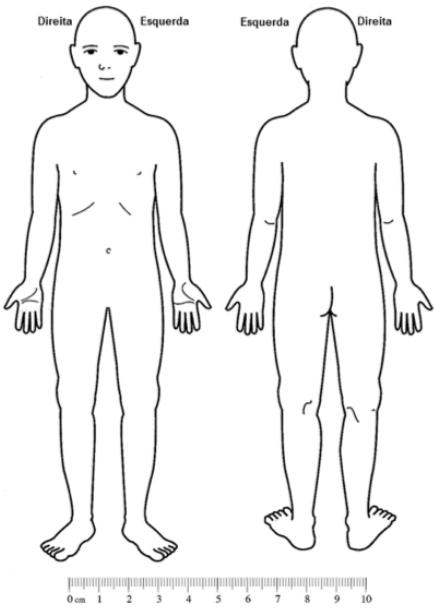
Versão portuguesa: Fernandes, Batalha, Perdigão, Campos e Oliveira, 2013

Código _____

Data _____

INSTRUÇÕES

1. Pinta nestes desenhos as áreas que mostram onde tens dor.
Pinta as áreas grandes ou pequenas conforme a dor que tens nesse local.



2. Faz um traço de cima para baixo nesta linha para mostrar quanta dor tens.

Sem dor | Dor pequena | Dor média | Dor grande | Pior dor possível

3. Indica ou faz um círculo nas palavras que descrevem a tua dor.

1
Aborrecida
Má
Horrível
Infeliz
Terrível
Desconfortável

2
Dorida
Magoa
Fraca e contínua
Como uma ferida
Sensível

3
Bate
Como uma chicotada
Como uma martelada
Como um murro
Palpita

4
Como uma mordidela
Cortante
Como um alfinete
Como uma faca afiada
Como uma alfinetada
Afiada
Como um golpe

5
Como uma bolha
Arde
Quente

6
Como uma cãibra
Esmaga
Como um beliscão
Belisca
Pressão

7
Faz comichão
Como um arranhão
Como uma picada
Arranha
Pica

8
Como um choque
Como um tiro
Corta

9
Dormente
Não deixa mexer
Inchada
Apertada

10
Muito desagradável
Mortal
Faz morrer
Mata

11
Faz chorar
Assustadora
Faz gritar
Aterradora

12
Causa tonturas
Enjoa
Sufocante

13
Não passa
Incontrolável

14
Sempre presente
Vai e volta
Vem de repente
Constante
Contínua
Dura sempre

15
Pára e recomeça
De vez em quando
Começa devagarinho
Às vezes
Sempre igual

Se quiseres, podes acrescentar outras palavras:

_____

_____

_____

_____

#S (2-9)	____ /37 =	____ %
#Af (10-12)	____ /11 =	____ %
#Av (1, 13)	____ /8 =	____ %
#T (14, 15)	____ /11 =	____ %
Total	____ /67 =	____ %

Pain In Child Health

FCT Fundação para a Ciência e a Tecnologia

Appendix G

Demographic Survey for Parents

Demographic Survey for Parents

This survey serves to identify the family composition of the children participating in the study project. The information provided may become very important during the art intervention with the children, contributing to the procedure and effectiveness of art intervention techniques for seven sessions. The administration of the survey will take place in the Hospital Santa Maria environment, after parents have given their formal consent to participate in the study project, respecting the principles of confidentiality and anonymity.

*(*Please circle one of the alternatives provided for each questions)*

Date: ___/___/___

Full Name of the parent _____

What is your age:

- 25-34 years old
- 35-44 years old
- 45-54 years old
- 55-64 years old
- 65-74 years old
- 75 years or older

Ethnicity origin:

- White
- Hispanic or Latino
- Portuguese Africans
- Asian
- Other

What is your level of education?

- No schooling completed
- Nursery school to 8th grade
- Some high school, no diploma
- High school graduate, diploma or equivalent

- Some college credit, no degree
- Bachelor Degree
- Master Degree
- Professional Degree
- Doctorate Degree

What is your marital status?

- Single, never married
- Married or domestic partnership
- Widowed
- Divorced
- Separated

Employment status: Are you currently…?

- Employed for wages
- Self-employed
- Out of work and looking for work
- A homemaker
- A student
- Military
- Retired
- Unable to work

What is you religion?

- Christian
- Muslim
- Catholic
- Buddhist
- Atheist
- Agnostic
- Non-religious
- Other (please specify)

Thank you!

Appendix H

Survey with Educators

Survey with Educators

How did art intervention fit into the overall treatment program?

…….

How did clients react to the art intervention?

…….

What was your overall impression about the implementation of group art intervention in this context?

……..

Did you witness any change in the children's behavior during the art intervention?

……..

When did you witness any change? Can you describe it?

……..

What was the parents' attitude toward the art intervention session with their children? Did it change?

…….

Did it help your work as educators, working with the children after the art intervention session?

……

How did you like this collaboration among educators, psychologists, nurses, and pediatricians?

……

Did you have any difficulties or discomforts when talking to your colleagues at the hospital during the art intervention procedure?

……..

What are some limitations of this project?

……..

What could be improved in regard to this collaboration?

……...

Free associations from this experience are very appreciated:

Please write here your thoughts

Appendix I

Formal Elements Art Therapy Scales: Rating Sheet

Formal Elements Art Therapy Scales: Rating Sheet

Picture #: _____

Rater: _____

FORMAL ELEMENTS ART THERAPY SCALE (FEATS)©
RATING SHEET

Linda Gantt, Ph.D., ATR-BC, & Carmelo Tabone, M.A., ATR

The FEATS uses scales that measures **more or less** of the particular variable. Look at the degree to which a picture fits the particular scale by comparing the picture you are rating with the examples in the illustrated rating manual. **You may mark between the numbers on the scales**. Approach the picture as if you did not know what it was supposed to be. Can you recognize indivicual items? If you have a picture that is hard to rate, do your best to compare it to the illustrations and the written descriptions. Do not worry whether your rating is the same a another rater's. Concentrate on giving your first impression to the variable being measured.

#1 - Prominence of Color							
Color used for outlining only	0	1	2	3	4	5	Color used to fill all available space
#2 - Color fit							
Color not related to task	0	1	2	3	4	5	Color related to task
#3 - Implied energy							
No energy	0	1	2	3	4	5	Excessive energy
#4 - Space							
Less than 25% of space used	0	1	2	3	4	5	100% of space used
#5 - Integration							
Not at all integrated	0	1	2	3	4	5	Fully integrated
#6 - Logic							
Entire picture is bizarre or illogical	0	1	2	3	4	5	Picture is logical

From: L. Gantt & C. Tabone, 1998, *Formal Elements Art Therapy Scale: The Rating Manual*, Morgantown, WV: Gargoyle Press, Copyright © 1998 Linda Gantt.

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#7 - Realism

Not realistic (cannot tell what was drawn)	0	1	2	3	4	5	Quiet realistic

#8 - Problem-solving

No evidence of problem-solving	0	1	2	3	4	5	Reasoning solution to picking apple

#9 - Development Level

Two-years-old level	0	1	2	3	4	5	Adult level

#10 - Details of Object and Environment

Less than 25% of space used	0	1	2	3	4	5	Full environment, abundant details

#11 - Line Quality

Broken, "damaged" lines	0	1	2	3	4	5	Fluid, flowing line

#12 - Person

No person depicted	0	1	2	3	4	5	Realistic person

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